

**Health informatics discourses and
the use of personal health
information:
Which piper, which tune, who pays?**

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Abstract

This study poses the question ‘*health informatics: which piper, which tune, and who pays?*’ to explore issues of power and influence in the use of personal health information in Australia. It draws on the work of Michel Foucault to explore how understandings about the use of personal health information facilitate its expanding use. Of particular interest is the way in which the health informatics community influences these understandings.

The study begins with the argument that increasing use of personal health information for secondary purposes is symptomatic of a broader societal trend of expanding information gathering and surveillance practices. It further argues that many of these practices move beyond accepted monitoring to become surveillance which may result in discrimination, disadvantage or social exclusion. The discipline of surveillance studies provides the context for exploring these arguments. Surveillance scholars draw on a range of sociological theories to explore and explain expanding uses of personal information in contemporary society. However, surveillance literature focuses primarily on the processes and consequences of these activities rather than on explaining how or why they occur. Michel Foucault’s conceptualisation of information gathering and surveillance as part of a network of modern disciplinary power provides an explanation of the how and why. Therefore, this study locates its analysis within the context of contemporary surveillance studies while utilising Michel Foucault’s arguments about the relationship between modern power, knowledge and discourse. This enables the study to explore links between the views of the health informatics community, the construct of the Australian privacy framework and systemic expansion of information gathering practices.

The study reviewed legislation and associated documents related to Australia’s privacy framework. It identified a privacy/public interest dichotomy as the

dominant approach to managing use of personal information and argues that this construct facilitates expanded uses of personal information on the basis of public interest. A Foucauldian influenced discourse analysis of the academic discipline of health informatics identified six discourses, all of which constructed information management issues in terms of this privacy/public interest balance. The study concludes that the health informatics community is a claim-making site with the potential to shape understandings about the use of personal health information in Australia. However, aspirational goals of the discipline work to discourage critical analyses of the privacy/public interest dichotomy. This creates the potential for the health informatics community, either wittingly or unwittingly, to support expanding use of personal information for activities that may result in increased monitoring and control of individuals, groups and the community as a whole.

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Chapter 1: Introduction

1.1 About the study

My point is not that everything is bad, but that everything is dangerous, which is not exactly the same as bad. If everything is dangerous, then we always have something to do. So my position leads not to apathy but to a hyper and pessimistic activism (Foucault, cited in Dreyfus & Rabinow, 1983, p. 231).

This study poses the question ‘*health informatics: which piper, which tune, and who pays?*’ to explore issues of power and influence in the use of personal health information in Australia. The study is particularly interested in the role the academic discipline of health informatics plays in shaping understandings about the problem of information management. Health informatics is a relatively new academic discipline and profession concerned with developing the sophisticated information systems that facilitate the collection, manipulation and dissemination of increasing amounts of personal health information. The health informatics community also contributes to high-level discussions regarding policies and guidelines for managing access to, and use of personal information. It is therefore in a position to influence both what should or should not be done, and what can or cannot be done with personal health information. The views of the community have potentially significant consequences both within the health care environment and, as integration of electronic systems increases, across the wider society.

The question was prompted by suggestions that the information gathering activities of many governments and organisations are moving beyond legitimate monitoring to become surveillance for the purpose of supervising and controlling citizens (Ball and Wood, 2006; Clarke, 1998; Lyon, 2001a; Marx, 2007). Of particular interest were suggestions that the framework of legislation, policies, procedures and protocols intended to manage access to personal

information in Australia is not an objective, neutral mechanism, but is shaped by political processes in which some actors have greater capacity to impose their understanding of the problem and solutions than others (Clarke, 2005; Stalder, 2002b). This study sought to explore these power relationships.

Surveillance literature provides the starting point for the study. Surveillance scholars draw on a range of modern and post-modern sociological theories to explain and critique expanding uses of personal information in contemporary society. Michel Foucault's arguments about panoptic power have been particularly influential in this discipline. Indeed, Foucault is considered as 'the pre-eminent theoretical figure for surveillance studies scholars' (Elmer, 2012, p. 21). However, while surveillance studies offer a comprehensive and informative description of expanding use of personal information, they do not encompass an analysis of the power relationships that shape our understandings and allow expanded uses to occur. Therefore, while drawing on surveillance studies to establish a context and rationale, this study moves beyond the parameters of the discussion in surveillance literature. In doing so, it addresses limitations in the way Foucault's work is applied in surveillance literature. It does so by drawing on his conceptualisation about the relationship between power, knowledge and discourse, locating the use of personal health information in the context of broader social issues of power and control. Foucault's ideas point to health informatics as a claim-making site with the capacity to support or challenge the expanding uses of personal health information.

This introductory chapter provides the context for the study. It identifies issues around use of personal health information and expands on the suggestion that the Australian privacy framework, which is intended to manage these issues, is shaped by more influential stakeholders to enable them to pursue their own goals and interests.

1.2 Context for the study

1.2.1 Sensitive yet valuable information

Health information is amongst the most sensitive of personal information. It includes details about a person's health status, disability, use of health services, and other personal information collected during a health care encounter. It comprises medical diagnoses and treatments but might also incorporate information about lifestyle factors including reports of domestic violence, drug use, cultural and religious beliefs, and socio-economic factors (Office of the Australian Information Commissioner, 2012). There are potentially serious consequences should this information be inappropriately disclosed, or used for purposes other than that for which it was collected (Clarke, 2006; Stein, 1997):

Medical records can reveal a history of drug abuse, a venereal disease, or a life-threatening illness. Psychiatric notes reveal inner fantasies...crimes... The information from genetic tests can reveal that a patient is susceptible to some diseases...If your medical records are disclosed, you can lose your insurance, you can lose your job, or even your marriage (Stein, 1997, p.224).

At the same time, the use of sophisticated electronic information systems to compile ever more comprehensive and integrated data repositories has seen personal health information become an increasingly valuable resource. While continuing to be integral to clinical care, the value of health information lies increasingly in secondary applications. These now extend well beyond the clinical uses for which the information was originally collected and include service planning and evaluation, policy development, health and medical research and commercial applications. While expanded uses fall largely within the health care sector, recent years have seen them extend to non-health care organisations, including commercial applications. The potential value of personal health information for these secondary purposes has long been realised. More than a decade ago Stein commented that 'insurance companies feel they have a legitimate right to review the medical record, or at least to

know what diagnoses and diagnostic tests are in it' (1997, p. 225). However, the capacity of electronic systems to collect and manipulate ever-larger amounts of data has seen a rapid increase in requests for access to health information for an expanding range of uses (Clarke, 2001; Greiner, 2005; Kruger, 2008; Phillips, 2003). Australian examples include:

- In 2005 CAMM Pacific, a company providing consultancy services to the pharmaceutical industry, sought to purchase de-identified patient data from Australian GPs via their software service provider.
- In 2008, the Australian Sports Anti-Doping Authority (ASADA) sought access to prescription records held by Medicare for evidence of athletes using performance enhancing drugs.
- An amendment to the *Health Insurance (Compliance) Bill 2009 (Australia)* granted Medicare access to patients' clinical information as part of their audit.
- In 2012, health insurance company BUPA Health Dialog announced that it wished to mine anonymous clinical data in the national e-health records system.

Views about this expanding use of personal health information are ambivalent. Many secondary uses are acknowledged as bringing significant benefits and people willingly contribute to the collection of their personal information in expectation of receiving these benefits in return. Thus, patients willingly consent to health care agencies collecting their personal health information, keeping this information in detailed records, sharing these records with other health professionals and even agreeing to sharing the information with other agencies, because they expect more effective and efficient health care in return (Levi & Wall, 2004; Lyon, 2001a; Lyon, 2004). Yet these perceived benefits mask inherent risks. Critics argue that these risks arise from the methods used to collect information, the type and volume of information that is collected,

who accesses the information, and the ways in which it may be used. They suggest that personal information, including health information, is now being used in ways that exceed legitimate need and that some uses have the potential to discriminate against, or disadvantage some groups and individuals (Ball & Wood, 2006; Clarke, 2006; Lyon, 2001a; Marx, 2007). The Australian Privacy Foundation (APF) expressed this concern regarding the Individual Health Identifier (IHI) legislation introduced by the Commonwealth Labour government in 2010. The legislation enables allocation of unique identifying numbers to all health care consumers and service providers in Australia. The intention is to facilitate service provider access to personal health information, resulting in more effective and efficient health care. However Fernando, on behalf of the APF argued that ‘unless patients can segment irrelevant past and/or sensitive information, they face significant risks to their privacy and may suffer damage to their personal lives’ (2009a). These concerns are not without foundation. A 2009 survey conducted by the Centre for Genetics Education at Royal North Shore Hospital found that some Australians were refused insurance protection because of their genetic make-up (Taylor et al. 2008). More recently, the Canadian Broadcasting Corporation reported instances of Canadians blocked from entering the United States after their records of mental illness were shared with the US Department of Homeland Security (Bridge, 2011).

Governments and the communities they represent are aware of the issues arising from increasing use of personal health information for secondary purposes. This is evident in the willingness of governments to introduce, monitor and review measures to oversee the use of personal information, and by the willingness of organisations and individuals to support these measures. Australia has implemented a complex and dynamic framework of federal, state and corporate legislation, policies, procedures and protocols, based on the *Privacy Act, 1988 (Cwlth)*. The framework seeks to protect the individual from

harmful consequences arising from the use of their personal information while also supporting appropriate use of this information for secondary purposes. This framework is framed as a process of balancing personal privacy with the public interest.

1.2.2 Balancing privacy and access to personal health information

In Australia, personal information is regarded as private and privacy is considered so important that it is protected by legislation. At the same time privacy is understood as a relative right which must be balanced against other rights and obligations. It is accepted that there are circumstances where the right to privacy will be overridden. This is acknowledged in the legislation which provides for privacy to be overridden ‘where required or authorised by law’ and ‘where reasonably necessary for [a range of public purposes]’ (Waters, 2009, p. 9). The legislation therefore protects the privacy of personal information unless and until:

- The information falls outside the parameters of the legislation
- An instrumentality that is exempt from the privacy legislation requires the information
- A matter of public interest is deemed more significant than individual privacy.

These provisions allow considerable latitude for privacy protection measures to be modified to permit expanded secondary uses of personal information. This latitude is regularly utilised as public and private sector organisations seek to change provisions for information use. Successful efforts to expand access to personal information in recent years include:

- In 2006, the Australian Federal Police were given new ‘notice to produce’ powers, enabling them access, without a search warrant, to information relating to investigation of not just terrorism, but any

‘serious’ offence. This power overrides privacy laws (Waters, 2006, p. 4).

- The *Healthcare Identifiers Act*, introduced in 2010, permits disclosure of the health identifier for a purpose permitted under another law. This provision has the potential to enable linking of Individual Health Identifiers to personal information held in other government departments (Sedgewick, 2010).
- In November 2011 the Commonwealth government signed a revised Passenger Name Record agreement with the European Union. Under the agreement, airlines are required to provide passenger information to Customs prior to arrival to assist in screening. Data can be shared with six other agencies including the Federal Police, ASIO and the Australian Crime Commission. The Australian Privacy Foundation argued that the agreement involves significant intrusion into the personal affairs of airline passengers entering and leaving Australia, without their express knowledge and consent (Dearne, 2011).

Requests for access to personal health information emanate from a broad spectrum of public and private sector organisations and there are different, often conflicting, views about who should have access to what kind of information for what purposes. While in principle supporting the need to protect citizens from possible negative consequences arising from use of personal information, organisations will argue that their particular request for access is justified. These requests are frequently couched in terms of community benefit or public interest. CAMM Pacific justified its purchase of de-identified information on the grounds that ‘de-identified patient data provides valuable insight into healthcare trends, including the spread of infectious diseases’ (Marshall, cited in Dearne, 2009). ASADA justified its attempt to access athletes’ prescription records in terms of its mandate to ‘promote pure performance’ and to ‘protect Australia’s sporting integrity’ (ASADA, 2008). The amendment granting Medicare access to patients, clinical information was defended on the grounds

that ‘the community had a right to ensure taxpayer money was well spent’ (Australian Privacy Foundation, 2009; Ludwig, cited in Dunleavy, 2008). BUPA Health Dialog argued that access to information in the electronic record would drive more effective, routine, targeted prevention activities for at-risk patients (Dearne, 2012). These intentions are clearly stated when requests for information are made and can therefore be scrutinised. However many organisations hold secondary or latent goals that are not always declared and that do not benefit other groups or society as a whole (Longstaff, 2005; Marx, 2005, Shaw & Greenhalgh, 2008). CAMM Pacific, for example, while justifying its purchase of personal health information on the grounds of public good, revealed a secondary, commercial goal when it stated that the harvested information ‘is not just for pharmaceutical companies; it is there for anybody to use – the government, the Health Insurance Commission. We will be selling it to anybody who wants to purchase it’ (Longstaff, 2005).

The pursuit of secondary goals is frequently attributed to profit-minded commercial entities but may be equally true of ‘researchers and other parties with “legitimate” public interests, who are often vehement in propounding the importance of their activities’ (Longstaff, 2005). A number of instances point to government departments and public and private health services holding undeclared secondary goals for the personal health information they collect. Carter points to an early electronic health record project that had the declared goal of minimising adverse events due to inappropriate prescribing. She notes that a major undeclared activity turned out to be electronic checking of consumer entitlements to medications at concession rates (Carter, 2000b). The Australian Privacy Foundation argues that HealthLink, the NSW electronic health record project, ‘is primarily for the benefit of administrators and researchers’ (Clarke, 2009). The term function creep is used to describe these expanding uses of personal information (Ball & Wood, 2006; Clarke, 1997; Lyon, 2001b). Function creep is considered to have occurred when personal

information is used for purposes not specified when the information was collected, not clearly related to the original use of the information, or used without the consent of the person to whom the information relates (Ball & Wood, 2006; Carter, 2000b; Lyon, 2001c). It is not a recent phenomenon and concerns about function creep have been raised for a number of years. Anderson (1998) points to an early incident in the United Kingdom where health information systems were adapted for uses other than health care: 'In 1996, the British Medical Association became concerned that police access to prescription records, which had been granted in order to trace doctors and nurses stealing heroin, was being used to search for illegal immigrants (p. 9). The tax file number (TFN), introduced in 1988, is widely cited as an example of function creep in Australia (Clarke, 1997; Crompton, 2001). When first introduced, the scheme applied exclusively to taxation administration. However, adjustments to the legislation in 1990 required a number of government agencies to share identity details of all of their clients, including provision of tax file numbers to Social Security for parallel matching. Agencies were also authorised to receive results of the matching process: 'the express limitation of the scheme to taxation uses has been progressively circumvented and additional uses have accumulated through function creep' (Clarke, 1997). Recent discussions have centred on the Individual Health Identifiers (IHI). Critics have long argued that there is potential for initiatives such as the IHI to expand to cover a range of activities including taxation control and law enforcement (Phelps, 2001; Puplick, 2005). A statement by the shadow treasurer during the 2010 Australian election campaign suggests that there is some foundation for these concerns:

A Coalition government would revive the controversial Howard-era plan for a national access card to identify every individual receiving government benefits, shadow treasurer Joe Hockey has revealed. But instead of everyone having a card, this time the identifier could be in electronic form (Colebatch, 2010).

These instances suggest that accidental dissemination or illegal use of personal information is not the only, or even most significant, threat posed by use of personal health information in contemporary society. A greater threat may well lie in expanding legitimate use, or function creep. Function creep occurs within the parameters of the privacy framework.

1.2.3 Systemic function creep

The privacy/public interest balance around which the privacy framework is constructed enables frequent challenges: 'Privacy legislation exists within the politics of rights, involving questions of balance. The politics of any given right is a contest between differing views about when a generally acceptable balance is reached,' (Ruschena, 2008, p. 425). In negotiating this balance, different views are not always given an equal hearing and the outcome, rather than being an acceptable balance, may result in function creep that favours some stakeholders and potentially disadvantages others (Clarke, 2005; Stalder, 2002a). Clarke, in an interview on the Australian Broadcasting Corporation's Radio National program, suggested this. He argued that there are 'many, many different ways in which the Privacy Act was designed to assist government and business' (2005). This allows the argument that function creep, rather than being the result of isolated incidents, is indicative of a more systemic and widespread process which sees personal information absorbed and used for an increasing range of purposes across all sectors of society.

Changes to the balance between individual privacy and access to personal information are justified in neutral, rational terms as necessary responses to changing social, political, economic or technical circumstances. They are often explained in reassuring terms referring to 'public interest', 'public good' and 'public safety'. Typical of such explanations is the Commonwealth Privacy Commissioner's 2012 ruling that allowed non-government organisations (NGOs) in South Australia to share information with other South Australian

NGOs and government agencies. Sharing of information is permitted ‘when there is serious risk of harm and it is in the public interest that they join in coordinating services for vulnerable families’ (South Australian Government, 2012). Yet while many expanded uses of personal information may be reasonable and justifiable, this study argues that the decision-making process is nevertheless a political one in which some actors have greater capacity to impose their understanding of the problem and solutions than do others. Sometimes this power is quite obvious. In 2006 the NSW government simply changed the NSW Privacy Regulation to allow its electronic health record system to operate as an opt-out rather than an opt-in model. In 2009, the Commonwealth government changed the *Australian Health Insurance (Compliance) Bill* to allow Medicare to access personal health records as part of its audit processes. These changes to the law were made despite strong opposition from many other stakeholders and interest groups (Clarke, 2009; Fernando, 2009a). They demonstrate the power of governments to simply move the goalposts to achieve their purposes. In other instances, the exercise of power is more subtle, with stakeholders constructing arguments in terms of enhanced physical health, national security, or the need to ensure fair distribution of scarce resources (Haggerty & Ericson 2000; Mariner, 2007). Critics point to expanding surveillance practices since 9/11 to illustrate this. They argue that a post-9/11 discourse of security and safety created the compliance required to introduce of a range of surveillance measures (Levi & Wall, 2004; Lyon, 2001b; Peissl, 2003). Levi and Wall argue that 9/11 was a pretext that enabled many governments to introduce more intrusive information gathering activities and surveillance of their citizens: ‘they offered an international and ready-made rationale for those proposals “under the table” that previously would not have been found acceptable politically’ (2004, p. 196). The security argument has also been used within the sphere of public health where the threat of bioterrorism and new natural epidemics like avian influenza are used to rationalise the broadening of public health surveillance

practices not previously countenanced. Mariner suggests that expanding public health surveillance is also facilitated by redefining community perceptions and attitudes so that behaviours and conditions such as smoking and obesity, once considered as falling within the sphere of personal choice, are now accepted as being within the sphere of public interest. This justifies a broadening of public health surveillance practices with individuals accepting, even welcoming, previously restricted uses of personal health information (2007, p. 390). Justifications can be very persuasive: 'Privacy is a weak argument in the face of overwhelming arguments for public safety, drug-control, accountability and welfare fraud control' (Gilliom, 2011, p. 500).

Expanding uses of personal information do not go unchallenged. A wide range of public and private organisations regularly and publicly critique the activities of government and business in both mainstream and academic literature. The ongoing discussions around the Commonwealth government's proposals to introduce the Individual Health Identifiers and Patient Controlled Electronic Health Records (PCEHR) illustrate this. Strong concerns have been expressed about the potential expanded use of the IHI and information contained in the PCEHR for unspecified secondary purposes (Fernando, 2009a; Sedgewick, 2010). Most discussions around the use of personal health information implicitly accept the construction of the issue as one of balancing individual privacy with other rights and interests. This focusses discussion on practical issues and situations to do with the implementation of the legislation, policies and protocols. These discussions highlight the ways in which laws and other forms of regulation both enable and constrain the use of personal health information. They also point to the ways in which political and institutional stakeholders seek to manipulate, modify or evade these regulations. Discussions also raise issues around the appropriateness of some expanded secondary uses of personal information. They do not, on the whole, question the construction of the issue as one of a privacy/public interest balance. Stakeholder groups

therefore contribute to the debate within managed parameters while at the same time reinforcing those parameters.

Yet some critics have questioned the privacy/public interest construct. More than a decade ago Bygrave challenged the view that protecting privacy inevitably conflicts with the interests of the broader community. He suggested that ‘the starting point should never be the assumption of the need for a trade-off’ (2001). Lyon questioned the relevance of privacy in the context of contemporary information management and surveillance practices: ‘Although privacy will continue to act as a simple mobilising slogan, as a concept it drifts further and further away from the realities it is supposed to address’ (2001c, p. 172). He argued that ‘political and economic consequences of loss of control over personal information are the real issue, not privacy. It is a problem that goes well beyond issues of intrusions of privacy,’ (Lyon, 2001c, p. 172). Some discussions, most notably within surveillance literature, have extended the analysis of information use beyond individual privacy to incorporate concepts such as group privacy, social justice, democratic participation and context-specific uses of personal information (Jacob, 2006; Juntti & Turnpenny, 2009; Lyon, 2007b; Nissenbaum, 2011; Shaw & Greehalgh, 2008). These discussions argue that the issues are far wider than individual privacy invasion, ‘invoking broader questions of social control and warning of the dangers of the creeping surveillance society’ (Bennett, 2011, p. 485). Bygrave hints at this when he states that ‘data protection laws generally do not attempt to assail most established systems of administration, organisation and control of information; rather, they tend to seek to manage these systems in a manner that makes them more palatable to (and hence, legitimate) from the perspective of the general populace’ (Bygrave, 2001, p. 282).

Drawing on these arguments, this study argues that information management as a privacy/public interest balance is a social construct, the result of the exercise

of power not just within the parameters of the privacy framework, but also in establishing those parameters in the first place (Bacchi, cited in Shaw & Greehalgh, 2008; Jacobs, 2006; Juntti & Turnpenny, 2009; Lyon, 2007d). The purpose of the study is to explore the influences that shape and support this construct. It focuses particularly on the role of the health informatics community.

1.3 Contribution of the study

There is no longer a search for meaning leading to the truth. Rather, the search exposes the way frameworks of truth develop and gain potency in the 'right way' of the form of 'best practice' to the exclusion of alternatives (Manias & Street, 2000a, p. 53).

The study contributes to ongoing discussions regarding the efficacy of the Australian privacy framework. It does so by focusing less on the practical issues and situations related to implementing the legislation, policies and protocols that comprise the framework, and more on issues of power and control that underlie the construction of the framework as a privacy/public interest balance. It challenges official representations of the framework as neutral, showing how policies around the use of personal information, including personal health information, are political processes that privilege some groups at the expense of others. Drawing on Foucault's work, the framework is represented as the product of a discourse which imposes a particular understanding of the problem and solutions of personal information management, while marginalising or excluding alternative views and constructs. This study, in problematising the privacy/public interest balance, allows for a more critical analysis of the expanding use of personal information than is permitted within the privacy framework.

The study also contributes to the discipline of surveillance studies. Gary Marx comments that 'while surveillance studies from law, economics and geography

suggest coherent sub-disciplines, sociologically tinged versions of the field are less so' (Marx, 2007). This study seeks to contribute to a more coherent sociological sub-discipline by incorporating a more comprehensive understanding of Foucault's work into sociological explorations of surveillance than is currently the case. While Foucault's work is frequently utilised in surveillance studies, there has been a tendency to adopt some aspects of his work, most notably the panoptic metaphor, without linking them to his broader conceptualisation of modern power and its relationship to knowledge and discourse. This has resulted in what Lyon describes as 'a fairly un-Foucauldian version of the panopticon being incorporated into existing analyses of discipline and social control without the baggage of discourse' (Lyon, 2004, p. 334). This study explains surveillance as a strategy of disciplinary power.

Within the academic discipline of health informatics, the study provides a critical analysis of the links between the collection of personal health information and broader social practices and power relations in Australia. The study argues that to effectively contribute to discussions about the use of personal health information, the health informatics community needs to incorporate a critical perspective that will 'identify and come to terms with inherent contradictions within the discipline and to take a stand on issues we often ignore – either unwittingly, but mostly wittingly' (O'Donovan & Roode, 2002, p. 29).

1.4 The analysis

The analysis begins with a critical review of the legislation, policy documents, reports and reviews related to Australia's privacy framework. It explores ways in which the privacy framework establishes parameters around what can and cannot be included in discussions about the collection and use of personal information. This provides the background for exploring health informatics discourses and the way they shape the approach of the academic discipline to information management issues. The second stage of the study is the analysis of

conference texts to identify health informatics discourses. A text analysis draws on Health Informatics Society of Australia conference proceedings for three periods between 1993-2009. The analysis then considers the relative influence of each discourse as indicated by evidence of institutional support, processes and relations. The final stage of the study analyses the way the discourses construct information management issues, particularly in relation to the privacy/public interest balance. The implications of this are considered in terms of the question ‘which piper, which tune, and who pays?’

1.5 Concepts

Discourse

While the study adopts Foucault’s conceptualisation of discourse, providing a concise definition of the concept is challenging. As Foucault himself observed:

instead of gradually reducing the rather fluctuating meaning of the word discourse, I believe I have, in fact, added to its meanings: treating it sometimes as the general domain of all statements, sometimes as an individualizable group of statements, and sometimes as a regulated practice that accounts for a number of statements (1972, p. 80).

The various ways in which Foucault used the concept are addressed as appropriate in the study. However, it is important to note from the beginning that the term is used not to refer to everyday conversation, but to groups of statements ‘which have some institutional force and which are thus validated by some form of authority; utterances classified as *the true*’ (Mills, 2003, p. 55). Foucault’s conceptualisation of the relationship between the subject and discourse should also be noted. From a Foucauldian perspective, ‘subjects are not the initiators of discourse, but are simultaneously the products of discourse and a means by which discourses are propagated’ (James, 2004, p. 17). The term discourse is often used as an inclusive term that encapsulates subjects. Thus, in this study, the statement ‘the discourse privileges technology’ does not imply that discourses have an independent free floating status independent of

human agency, but rather to indicate the speaker as located within the discursive formation and shaped by that formation. At the same time, it is emphasised that there is always the possibility for agency as ‘individual or collective subjects are faced with a field of possibilities in which several ways of behaving, several reactions and diverse comportments may be realised’ (Foucault in Dreyfus & Rabinow, 1983, p. 790).

Data and information

Within the discipline of health informatics, a distinction is made between data, information and knowledge. Data generally refers to raw facts as in descriptions, observations, images or sounds. Data that is interpreted, organised or structured in a meaningful way becomes information. Bringing understanding to information produces knowledge. The legislation, policies and protocols associated with the privacy legislation do not clearly differentiate between data and information, with the terms sometimes used interchangeably. A distinction is made in the legislation between de-identified data and personal information. The definition of personal is based on the presence of ‘a quality of *intrinsic identifiability*, meaning that what can be used to identify a person must be contained in the information itself’ (Thomson, 2005, p. 315). Information that lacks this characteristic is considered as de-identified. From the health informatics perspective, de-identified data may be information if it is combined in ways that give it meaning. Within this study the terms reflect the context in which they are used.

Surveillance and dataveillance

Within surveillance studies a distinction is made between hard surveillance and soft surveillance (Clarke, 2003, Levi & Wall, 2004). Hard surveillance is direct, physical surveillance which utilises sophisticated technologies such as scanning equipment and CCTV, while soft surveillance primarily collects and analyses electronic data and information (Levi & Wall, 2004). Roger Clarke (1987)

coined the term dataveillance to refer to this latter practice. In recent years, dataveillance has become an integral feature of daily life (Ball & Wood, 2006; Clark, 2003; Lyon, 2001c; Marx, 2007). Medical records, electoral rolls, credit cards, even library cards, provide information which confirms identity, establishes the basis for access to goods and services and helps to identify those engaged in illegal activity. In doing so, dataveillance constructs an additional *self* which exists in databases. In contemporary society many decisions affecting the individual are made on the basis of the data-self. This has prompted Lyon to suggest that data surveillance 'is the fastest growing and almost certainly the most controversial kind of surveillance' (Lyon, 2007a, p. 171). Secondary use of health information falls within the domain of dataveillance.

Health informatics

Health informatics is a relatively new academic discipline. The Australian Health Informatics Education Council (AHIEC) has described health informatics as 'the body of knowledge that concerns the acquisition, storage, retrieval and use of information in, about and for human health, and the design and management of related information resources, devices and methods to advance the understanding and practice of healthcare' (2009, p. 19). Telehealth and e-health are also used in the context of health information management. These terms refer more to the technical systems used to collect and manipulate personal health information. As such, they are considered to be a sub-set of the discipline of health informatics. This study focuses on personal health information rather than the technologies.

Information privacy

Dimensions of privacy include physical privacy, privacy of communications, territorial privacy and information privacy (Clarke, 1997). Physical privacy

refers to events such as physical searches, use of DNA and compulsory immunisation. Privacy of communications is delineated in terms of monitoring of mail, telephones and, increasingly, email and internet activity. Territorial privacy refers to intrusions into domestic and other environments, and information privacy involves access to, and use of, personal information (Clarke, 2006; Crompton, 2001). Early definitions of privacy focused on physical privacy, distinguishing particularly between the domestic/private and the public spheres of life. The increasing capacity for information and communication technology to gather and store data has seen the focus moving more and more towards information privacy. There are a number of federal and state laws relating to these various dimensions of privacy but the privacy legislation introduced by Australian government deals specifically with privacy. Information privacy is the focus of this study.

Privacy framework

The term privacy framework is used throughout this discussion to refer to the complex array of legislation and policies, guidelines and protocols that have been introduced in the attempt to manage the use of personal health information in Australia. The responsibility for privacy law and practice is shared by federal and state governments and territories. These have enacted a range of measures to manage privacy. Depending on the circumstances, health information management activities may be affected by national and/or state and territory law. This situation is made more complex because, in addition to specific legislation, a range of other statute law and common law deals with privacy. This means that oversight of privacy issues may be administered by multiple agencies rather than by a single designated privacy watchdog. While this range of provisions might be considered too chaotic to be described as a framework, the term is used to reinforce the complex and varied measures that govern the use of personal health information.

Security, privacy and confidentiality

Security, privacy and confidentiality are related concepts. Security refers to measures, both technical and non-technical, implemented to maintain the privacy and confidentiality of data and information. There is no definition of privacy in the Australian privacy framework. Privacy has been defined in health discussion as ‘the right of an individual to limit access to personal information’ (Conrick, 2006, p. 341), while confidentiality refers to ‘the expectation that the information collected will be used for the purpose for which it was gathered’ (Bialorucki & Baine, 1992, p. 53).

1.6 Chapter outlines

Chapter Two provides the starting point for the analysis. The chapter reviews the explanations for, and analyses of, expanding information gathering and surveillance practices within the literature. These analyses range from optimistic explanations found primarily in non-academic literature to more critical analyses located primarily within the discipline of surveillance studies. The chapter both reviews the contribution of these perspectives to an understanding of expanding uses of personal information use, and identifies the limitations of these perspectives for the specific focus of this study. Foucault’s ideas about the relationship between power, knowledge and discourse are presented an appropriate theoretical framework for the study. The final section of this chapter reviews other discourse analyses of health informatics.

Chapter Three outlines the methodological approach of the study. A Foucauldian based theoretical framework points to a Foucauldian influenced discourse analysis as the appropriate methodology. The chapter begins by briefly expanding on this rationale before discussing the specific methodology and methods used in the study. Issues and limitations related to the use of this approach in this study are identified and discussed.

Chapters Four and Five provide the background for the analysis of the health informatics discourses. These chapters focus on the Australian privacy framework. Chapter Four outlines the federal and state legislation and discusses the concepts on which this legislation is based. It explores ways in which the privacy framework establishes parameters around what can and cannot be included in discussions about the collection and use of personal information. Chapter Five summarises the discussion and debate generated by the operation of the framework. It points to the way these commentaries, including critical commentaries, implicitly accept the privacy/public interest balance. The analysis explores evidence of the power of some groups to shape the privacy framework and its implementation.

Chapter Six begins with a brief overview of the historical narrative of the development of health informatics before moving on to discuss the six discourses that this study argues interacted to shape the discipline. The chapter describes and differentiates these discourses as they appeared in the conference texts. Each discourse is described in terms of its focus, the way it constructs information management as the object of knowledge, the themes and strategies it uses to establish parameters within which discussion can occur, and the subjects and status positions constructed by the discourse. This chapter does not address the ways in which the discourses construct information management/privacy issues. As a particular focus and significant issue for the study, this construct is addressed separately in Chapter Eight.

Chapter Seven maps the institutional processes and relations of the discipline of health informatics for the period of each text analysis. In doing so, it considers the relative power of the discourses in generating and shaping these relations and practices. To emphasise that the analysis does not approach the development of health informatics as an evolutionary process, the study adopts Roth's suggestion that 'a history *of* the present means writing a history *in* the

present,' (1981, p. 43). Each of the three periods included in the analysis of conference texts is approached as a representation of the discourses and the discipline at that particular point in time.

Chapter Eight describes the way the discourses construct issues around the collection and use of personal health information. It notes that while discourses are generally understood as competing to impose their particular understandings about an issue, the six discourses in this study accepted the privacy/public interest construct of the Australian privacy framework. The chapter discusses the implications of this finding.

Chapter Nine draws together the various strands of the study and the implications of the answers to the research questions. It addresses the overarching study question, '*health Informatics: which piper, which tune, who pays?*'

Chapter 2: Explaining the use of personal information

2.1 Introduction

This chapter reviews explanations for expanding use of personal information and surveillance. It begins with a brief summary of the emergence of the *information society* which has seen information become a valuable resource, generating wealth for individuals, companies and countries in the same way that manufacturing did during the industrial society. This chapter then reviews various explanations and analyses of the information society. These range from optimistic representations found primarily in non-academic literature to more critical analyses located within the discipline of surveillance studies. The discussion focuses on the surveillance studies literature which offers a comprehensive critique of the growth and complexity of contemporary surveillance and information gathering practices. While informative, these analyses focus primarily on the processes and consequences of surveillance rather than exploring the political processes that shape our understandings about appropriate information gathering and surveillance practices, the focus of this study. The work of Michel Foucault is introduced as a useful theoretical and methodological framework for the study. Foucault is used to establish links between discourses within the discipline of health informatics, the operation of the privacy framework, and the broader practices of surveillance and social control as elements of modern power. The final section of the chapter briefly reviews relevant discourse analyses within the academic discipline of health informatics. In doing so, the study acknowledges that findings from discourse analyses are not generalisable to other situations, other discourses or other people, since they are ‘a matter of the social, historical and political conditions under which statements come to count as true or false’ (McHoul & Grace,

1993, p. 31). At the same time, synergies between similar studies may reinforce or support the observations arising from this research.

2.1.1 The information society: Expanding use of personal information

The shift from viewing personal health information as useful in an individual clinical context to viewing it as a valuable resource for secondary applications was part of a much broader twentieth century trend. This trend saw the collection and use of ever-increasing amounts of personal information across a wide spectrum of public and private sector organisations (Ball & Wood, 2006; Lyon, 2001a; Marx, 2007; Webster, 2006). Higgs (2001) illustrates this in his historical review of the British Government Records Office (GRO). Higgs traces the evolution of GRO activities from ‘keeping nominal records providing actors in civil society with proof of their own identity, to centralised record keeping and surveillance which decided eligibility for goods and services at the level of the nation state’ (2001, p. 191). This expansion occurred across private and public sector organisations around the world so that by the late twentieth century personal information of all types had become a valuable resource: ‘generating, processing and transmitting information are the information society’s main sources of economic productivity, of cultural change and political power’ (Van Est & van Harten, 2002). Emerging information management technologies facilitated this process to the point where, in contemporary society, sophisticated electronic information systems are able to collect, analyse and disseminate personal information for activities ranging from border control to assessing eligibility for government services to scrutinising consumer spending (Ball & Wood, 2006; Lyon, 2001a; Marx, 2007; Webster, 2006). As Lyon observes, ‘it is difficult to exaggerate the massive surge in the use of personal data from the 1970s to today. There is a constant growth in the volume of personal data that flow locally, nationally and internationally through electronic networks’ (2007, p. 16).

Health care services epitomise this escalating use of personal information. In the nineteenth century, the family doctor was the key health care provider. Hospitals were small, offered little that could not be provided at home, and often had close links with the local community. The amount of personal health information collected was limited and often not systematically recorded. Throughout the twentieth century, biomedical knowledge expanded, resulting in an increase in the number of medical specialisations and a growth in complex tests, treatments and interventions. This, together with the growing involvement of government and large private organisations such as health insurers, saw health care become organised into large, cumbersome, complex and increasingly expensive systems. By the end of the twentieth century health care in Australia was structured into large, bureaucratic systems, comprising a mix of public and private providers in community and hospital settings. Patients moved within and between departments and services. Clinical and administrative data and information also moved within and across departmental and service boundaries:

Clinical care is typically delivered in a corporate environment in which patient information is centralised in a 'unit record' and accessed by a range of administrative functionaries and health professionals who collaborate in caring for the patient. Information will be shared widely within the 'treating team' (Magnusson, 2004, p. 682)

This complex environment, and the amount of information generated within it, was problematic for traditional paper record management systems. Increasingly sophisticated information and communication technology offered the means for resolving many of these problems and at the same time created the tools to enable government and health organisations, research groups and even commercial companies to access personal health information for an expanding range of secondary purposes. Today, health information systems and associated applications are used for diverse clinical, educational, administrative, research

activities and commercial activities. Many of these uses were not thought of when electronic systems first began to be used for managing personal health information.

This phenomenon was repeated across many sectors of contemporary society. By the last decades of the twentieth century the practices had become so widespread and routine that the term ‘information society’ was coined to describe them (Earl et al., 2009; Wood et al., 2006). Garfield defines an information society as one in which ‘we take for granted the role of information as it pervades and dominates the activities of government, business and everyday life’ (1979, p. 609). The information society has generated much discussion ranging from optimistic embracing of the information society to critical analyses warning of the dangers of surveillance and control. Optimistic interpretations explain expanding use of personal information as integral to an effectively functioning modern society, arguing that this process brings widespread benefits to individuals and communities alike. Critical analyses temper these views, pointing to power and control as inherent elements in information gathering and surveillance activities and drawing attention to the potential for discrimination and disadvantage arising from some uses of personal information.

2.2. The information society: It’s all good

The concepts ‘information society’ and ‘information age’ originated within academic communities as social scientists sought to understand and explain the changes occurring in advanced capitalist countries throughout the late twentieth century. These changes were associated with the move from industrial-based economies to information economies with analyses focusing particularly on exploring the impact of information technology and its expanding capacity to collect increasing amounts of personal information (De Miranda, 2005; Burnett, Senker & Walker, 2009). The focus is indicated in the *Information Society*

Journal, which represents itself as a ‘key critical forum for leading edge analysis of the impacts, policies, system concepts, and methodologies related to information technologies and changes in society and culture’ (*Information Society Journal*, 2012). Webster describes the community of scholars studying the information age as ‘social thinkers engaged in trying to understand and explain the world in which we live, with a manifestly important feature of this being change in the informational realm’ (Webster, 2006, p. 3). These social thinkers were located in diverse academic fields and while there are references to a discipline of the information society, Raban, Gordon and Geifman argue that even today the field is ‘at a fairly early stage in its evolution into a mature research discipline’ (2011, p. 375).

While the academic discipline may be a work in progress, ‘the political and economic communities have taken the information society idea to their hearts’ (Webster, 2006, p. 2). This is evident in the number of publicly funded instrumentalities and events that have been established with the stated aim of furthering the information age. At the international level, these include the UNESCO-sponsored World Summits on the Information Society, and *Europa*, the European Commission’s Information Society web portal. These bodies are in a position to significantly influence the approach of governments and public and private organisations to the collection and use of personal information for secondary purposes. The literature from these sources is overwhelmingly optimistic, speaking of the leisure society, electronic democracy, even the end of work, and emphasising the potential for technology to gather and use information in ways that will enrich the lives of individuals and communities around the world (Earl et al., 2009; Wood, 2006). Kofi Annan, Secretary-General of the United Nations, expressed this general optimism about the information society in his opening address to the 2003 World Summit on the Information Society:

Technology has produced the information age. Now it is up to all of us to build an Information Society. From trade to telemedicine, from education to environmental protection, we have in our hands, on our desktops and in the skies above, the ability to improve standards of living for millions upon millions of people (Annan, 2003, p. 1).

In the health care sector this optimism is reflected in expectations that the information age will provide enhanced levels of care, structural reform and organisational modernisation, thereby resolving many of the major challenges that healthcare organisations are increasingly grappling with (Cornford & Klecun-Dabrowska, 2003; Hewett, 2007).

Computerisation of health records may give rise to a new health paradigm in which patients, doctors and administrators all have potential to reap many benefits associated with a rich and sophisticated informational environment (Longstaff, 2005, p .ii).

While these discussions emphasise the widespread benefits of the information age, they do acknowledge the possibility of negative consequences for some individuals as a result of the use of their personal information. Yet this possibility is minimised and justified in terms of the greater benefits accruing to the wider community: ‘the fact that some benefit from technology more than others is a necessary by-product of the social order,’ (Nolan, 2010). In Australia, the privacy framework, introduced to manage access to personal health information, reflects this perspective. The framework acknowledges that some individuals may suffer negative consequences as a result of the use of their personal information, but suggest that this danger is acceptably low given the broader interests of the ‘public good’ or ‘public safety’ (Office of the Privacy Commissioner, 2009).

The generally optimistic analyses of the information society are reflected in research and development communities in both academic and commercial

environments. The focus is on research and development to manage and disseminate the benefits of the information age:

The new ICTs are a powerful yet neutral tool that can be used to address a host of issues in every community- their real power, therefore, lies in their ability to support holistic development that promotes long-term social and economic benefits (Harvard University, 2012).

Research programs therefore tend to focus on addressing the practical issues that will 'narrow the digital divide that accentuates disparities in development, to guarantee the free flow of, and equitable access to, data, information, best practices and knowledge in the information society; and to build international consensus on newly required norms and principles' (Boafo, 2003, p. 4). However, while generating knowledge to facilitate more effective use of information technologies, these studies tend to ignore issues of power, conflict, or disadvantage that may be associated with their use. The field of surveillance studies offers more scope for exploring these issues.

2.3 Surveillance studies: Some good, some not so good

Surveillance literature uses the terms 'surveillance' and 'surveillance society' to refer to those same trends in information gathering and monitoring practices that gave rise to the term information society. Discussions about surveillance and surveillance society have been appearing in the literature for as long as discussions about the information society. These studies challenge the representation of the information society as bringing widespread benefits and opportunities, arguing that surveillance practices produce benefits and disadvantages that are not distributed equally and which therefore have implications for inequality and for social justice (Lyon, 2001c; McCahill, 2007; Marx, 2005). Marx notes that even when introduced for benign reasons surveillance 'is still applied in nonreciprocal hierarchical settings where goals conflict' (Marx, 2005, p. 380).

Surveillance studies literature is prolific and wide-ranging, drawing on multidisciplinary sources, including law, political science, sociology and philosophy (Bennett, 2011; Jenness et al., 2007; Lyon, 2001c). This multidisciplinary base makes for a fragmented, complex and diverse field within which scholars both explore expanding surveillance practices while debating the nature of their relatively new discipline. The debate encompasses questions about the scope, focus, issues and theoretical underpinnings of surveillance studies with different views expressed about the possibility or desirability of a single, united approach to the field (Allmer, 2011; Fuchs, 2011; Haggerty et al., 2011; Marx, 2007; Barnard-Wills, 2009). While Haggerty et al. argue that the ‘sheer complexity of the topic renders arriving at an overarching theory of how surveillance operates inherently difficult’ (2011, p. 233), Marx argues that the field needs, at the least, ‘greater agreement (or well-articulated disagreements) on what the central questions and basic concepts are’ (2007, p. 126). The complexity of these discussions is acknowledged. It is not the intention in this study to engage in a comprehensive analysis of these complexities but rather, to draw on the discussion to provide insight into the issues relating to the use of personal health information.

Surveillance scholars have adopted different approaches in their efforts to explain and clarify both the complexity of contemporary surveillance and information gathering practices and the undoubtedly related complexity within their field. Approaches range from relatively straightforward historical analyses (Bennett, 1996; Lyon, 2001a), to the development of typologies that differentiate conceptualisations of surveillance and the key concepts used to explain it (Allmer, 2011; Bennett, 2011; Fuchs, 2011; Gilliom, 2011). Fuchs differentiates between the conceptualisation of surveillance as negative or neutral. Neutral concepts ‘see surveillance as an ontological quality of all societies or all modern societies and identify, besides negative aspects, also actual positive qualities of surveillance’ while negative surveillance concepts

‘consider surveillance to be inherently connected to domination and coercion’ (Fuchs, 2011, p. 110). Allmer differentiates between Foucauldian influenced panoptic explanations and non-panoptic explanations (Allmer, 2011, p. 569). Panoptic approaches represent surveillance as negative, while non-panoptic definitions define surveillance in a neutral way (Allmer, 2011, p. 568). These typologies analyse the same body of literature but use a different lens. By integrating the analyses, it is possible to broadly differentiate surveillance studies on the basis of neutral/non-panoptic and negative/panoptic approaches.

Surveillance literature can also be differentiated according to the way privacy is conceptualised, particularly the relevance or usefulness of privacy and other related concepts for explaining surveillance. This literature is differentiated between those who argue that privacy is no longer an adequate concept for dealing with the complexity and scope of contemporary surveillance (Crompton, 2001; Gilliom, 2011; Stalder, 2011) and those who argue that while it may not be adequate to explain all surveillance activities, privacy is nevertheless a central and valuable concept (Bennett, 2011; Regan, 2011).

Thus, the complex surveillance literature can be explored by adopting a historical perspective, by differentiating between Foucauldian influenced negative/panoptic approaches and neutral/non-panoptic approaches, or by differentiating the conceptualisation of privacy as an adequate or inadequate concept for analysing contemporary practice.

2.3.1 Historical analyses

Historical analyses trace the expansion and intensification of surveillance practices from individual institutional settings to interconnected surveillance networks while also highlighting the diverse theoretical perspectives that are used to frame these analyses. These analyses trace surveillance practices from their beginnings as primarily activities of state bureaucracies. They show how,

as smaller, less expensive, decentralised information systems developed, these practices spread to the private sector, resulting in society wide networks of surveillance. In his historical overview, Lyon (2001a, p. 109) notes that both modern and postmodern theories are used to explain surveillance. Modern sociological analyses are influenced by Marx, Weber and Giddens. These link surveillance practices to the power structures of modernity, particularly to bureaucratic rationalisation, political economy, and the nation state (Ball & Wood, 2006; Lyon, 1994; Marx, 2005). Analyses explore environments ranging from government bureaucracies (Higgs, 2001; Laudon, 1986; Rule, 1973) to workplace surveillance (Introna, 2000; Rule, 1992) to surveillance of welfare recipients (Ball & Wood, 2006; Gilliom, 2011; Henman & Dean, 2002). Lyon suggests that these theoretical perspectives were appropriate for explaining surveillance practices of modernity, but proved inadequate when increasingly sophisticated technology enabled surveillance networks to transcend individual organisations to enable more widespread and intrusive forms of information gathering. He argues that the work of postmodern theorists is more useful for explaining these more widespread, complex and subtle surveillance practices (Lyon, 2001a). Particularly influential in postmodern analyses are Foucault's panoptic metaphor, Poster's superpanopticon and the concept of the surveillant assemblage used by Haggerty and Ericson (Nolan & Levesque, 2005; Pecora, 2002; Vaz & Bruno, 2003; Williams & Johnson, 2004). These scholars represent surveillance as a network that is dispersed throughout society, and operated out by government and private organisations in pursuit of their particular goals or interests. They also argue that 'surveillance power is bi-directional and is more-often-than-not triggered by individuals themselves' (Lyon, 2007d, p. 110).

Historical analyses enable the identification of themes and trends within the literature. Although offering different explanations, these analyses generally link expanding information gathering and surveillance practices to the

increasing dependence of modern organisations on personal information as a resource. Analyses also agree that information gathering and surveillance practices will inevitably expand. Scholars differ in their interpretation of this. More benign explanations view surveillance as an essential activity, 'a means of maintaining order and coordinating the activities of large populations' (Lyon, 1994, p. 37). More conflict-oriented interpretations represent surveillance as tool used to benefit institutions, organisations or groups in a society of hierarchical power structures and conflicting goals. From this perspective, the consequences of surveillance are argued to confer benefits for some, while excluding or discriminating against others. Whether benign or otherwise, it is accepted that surveillance activities have an impact on the life chances and opportunities of individuals and groups (Clarke, 1998; Haggerty & Ericson, 2000; Lyon, 1994, 2001a; Marx, 2005; Pecora, 2002; Peissl, 2003).

A second theme relates to the increasing practice of automated decision-making based on data stored in electronic systems. Personal data is collected and aggregated to create electronic profiles which then become the basis for decision-making: 'Decisions may be taken on the basis of the data-self which are to the detriment of the real self' (Poster, 1990, p. 98). Concerns are expressed that accumulated knowledge may not be accurate but may nevertheless have an impact on the individual (Ball & Wood, 2006; Clarke, 1998; Da Costa et al., 2006; Gandy, 1993; Levi & Wall, 2004).

Social justice and personal privacy are also constant themes within surveillance literature. Jenness et al. (2007, p. vii) differentiate these in terms of macro-level and micro-level studies. A social justice theme is evident in macro-level analyses that seek to understand the relationship between surveillance and power, the cultural processes which facilitate surveillance, and the consequences of surveillance for individuals and groups. Macro-level studies utilise the panoptic metaphor and the concept of 'the gaze' to explore the

relationship between surveillance and power. Primary concerns at the micro-level are consequences of surveillance practices for personal privacy and individual rights. The collection of personal information is viewed as undermining privacy (Haggerty & Ericson, 2000; Levi & Wall, 2004; Lyon, 1994, 2001b; Marx, 2005). These themes are evident in the typologies exploring the nature and focus of surveillance studies.

2.3.2 Someone is watching: Negative/panoptic

Surveillance as a negative concept is ‘inherently linked to information gathering for the purposes of domination, violence and coercion’ (Fuchs, 2011, p. 114). Authors adopting this perspective do not argue that all information gathering activities are inherently negative. They acknowledge that some information gathering activities do have benefits, or are at least neutral, but they differentiate between the positive and negative activity by referring to consensual monitoring and non-consensual surveillance (Ball & Wood, 2006; Barnard-Wills, 2009; Gandy, 1993; Henman & Marston, 2008). Fuchs explains monitoring as ‘information processing that aims at care, benefits, solidarity, aid, and co-operation, benefits all, and is opposed to surveillance’ (2011, p. 128), while surveillance is ‘a specific form of information gathering for the purpose of domination and control’ (2011, p. 128). Studies adopting a negative definition focus on surveillance for the purposes of control rather than on consensual monitoring. Definitions use terms such as ‘discriminatory’, ‘control’ and ‘inequality’ to emphasise this focus:

- It is a discriminatory technology that allocates options and opportunities on the basis of those measures and the administrative models that they inform (Gandy, 1993, p. 15).
- Surveillance is routine ways in which focused attention is paid to personal data by organisations that want to influence, manage, or control certain persons or population groups (Lyon, 2003, p. 5).

- We need to approach the issue of surveillance as a relative concept with unequal processes and outcomes (Henman & Marston, 2008, p. 187).

Discussions focusing on the negative aspects of surveillance argue that many consensual monitoring activities are moving beyond legitimate need to become non-consensual surveillance. A strong social justice theme is evident in these discussions as the consequences of surveillance practices of welfare organisations, employers, police and government agencies are discussed in terms of power, control, discrimination and exclusion (Ball & Wood, 2006; Gilliom, 2011; Henman & Marston, 2008; Higgs, 2001; Williams & Johnson, 2004).

The panoptic metaphor, adapted from the work of Michel Foucault, has been particularly influential in explorations of the negative impact of surveillance (Barnard-Wills, 2009; Bennet, 2011; Pecora, 2002; Poster, 1990; Vaz & Bruno, 2003; Williams & Johnson, 2004). Haggerty, Wilson and Smith observe, ‘no theorizing of surveillance can sensibly commence without acknowledging the sustained influence of Foucault’s panoptic model’ (2011, p. 232). Based on Jeremy Bentham’s concept of a prison constructed with central watchtower surrounded by cells, the metaphor is used to emphasise modern surveillance as an all-encompassing gaze where ‘power is vested in the everyday practices of administrators and professionals who monitor and control through continuous, asymmetrical and relatively invisible surveillance’ (Gilbert, 2003, p. 39). In studies of health care, the panopticon is explained as comprising a combination of physical facilities, observation, and recording of activities. Physically, facilities are structured around centralised observation points that allow surveillance of everyone within the facility. This combines with regular observation and recording of activities to create an all-encompassing panoptic gaze (Gastaldo & Holmes, 1999; Stevenson & Cutcliffe, 2006). Analyses have identified these surveillance practices as well-established in environments such as psychiatric or intensive care wards but note that they extend across all

environments, even to the waiting room of the general practitioner, (Gastaldo and Holmes, 1999; Stevenson & Cutcliffe, 2006). Studies have also identified the role of clinical staff in panoptic surveillance:

In the intensive and acute care units, the individuals are visible and submissive to the clinical gaze and constant surveillance. The 'nursing gaze' dictates specific methods of observation, techniques of registration and procedures for investigation. Thus the nurse participates in the construction of a sophisticated apparatus of surveillance (Gastaldo & Holmes, 1999, p. 237).

Studies have applied the metaphor to surveillance of health professionals, arguing that audit trails, performance measures and other monitoring systems, while justified as contributing to more effective and more efficient health care, are also tools for routine monitoring and control of health professionals. Scott et al., in their study of the NHS in Britain, argued that 'the social impact of clinical information systems and technology in healthcare is partly a politico-administrative apparatus designed to make professionals more visible and accountable. This new visibility pushes physicians to the periphery of Bentham's panopticon a place previously occupied only by patients and medical menials' (2007, p. 62).

While Lyon initially suggested that 'sufficient empirical work has been done to show the relevance of at least some aspects of the panopticon to electronic surveillance' (1994, p. 58), its use has not been universally supported (Bennett, 2011; Fuchs, 2011; Marx, 2007). Critics argue that this metaphor does not adequately capture the complexity and multiplicity of modern surveillance. They argue that the metaphor represents power as hierarchical, centralised and primarily exercised by the state, whereas contemporary surveillance practices extend well beyond state administered-institutions to society-wide networks incorporating state and private sector organisations. Concepts such as super-panopticon and electronic panopticon have been introduced to counter these criticisms. These concepts are intended to convey the expanding panoptic gaze

from the immediate physical environment into the realm of electronic or dataveillance (Gandy, 1993; Poster, 1990; Webster, 2006): 'Today's circuits of communication and the databases they generate constitute a Superpanopticon, a system of surveillance without walls, windows, towers or guards' (Poster, 1990, p. 93 cited in Fuchs, 2011, p. 117). The electronic panopticon creates a data-self from information collected from personal documents. The information created about the data-self is used to determine eligibility for goods and services. The super-panopticon and electronic panopticon are also considered inadequate concepts since they continue to incorporate assumptions that power differentials are always present and that surveillance necessarily serves the goals of the powerful against the less powerful.

Critics of the explanations drawing on the panoptic and associated metaphors argue that both theory and research place too much emphasis on the power/conflict struggles and negative consequences of structural surveillance. They argue that these explanations simplify or neglect the complexity and multiplicity of surveillance goals, the interaction/negotiation between agents and subjects of surveillance, and the connection between micro-level activities and the macro-level social structures and institutions of surveillance (Marx, 2007; Bennett, 2011). Despite these criticisms, the panoptic metaphor and its various permutations continue to influence surveillance studies (Fuchs, 2011; Gallagher, 2010). Haggerty suggests that 'the panopticon has come to exert an oppressive influence over the field as the dominant model of surveillance' (cited in Gallagher, 2010, p. 263). Marx also argues that this negative perspective sees 'most studies deal with contexts of conflict, domination and control. The extensive use of surveillance in other settings for goals involving protection, management, documentation and strategic planning' (Marx, 2005). Discussions representing surveillance as neutral incorporate this expanded view and in doing so, address some of the criticisms made of the negative-focused explanations.

2.3.3 Janus face: Neutral definitions

‘One claim of neutral surveillance concepts is that there is a positive side of surveillance or that there is a negative as well as a positive side of surveillance’, (Fuchs, 2011, p. 112). This is essentially the same position taken by those adopting a negative definition. However, rather than focusing on the negative aspects, those adopting a neutral definition of surveillance include both consensual monitoring and surveillance in their considerations. These discussions present a view of surveillance as concerned not just with control and domination but also with maintaining social order, ensuring equitable access to goods and services and promoting the well-being of citizens. This broader approach is indicated by the use of more neutral terms such as ‘observation’ to ‘govern’:

- Surveillance involves the observation, recording and categorisation of information about people, processes and institutions (Ball & Webster, 2003, p.1).
- Surveillance involves the collection and analysis of information about populations in order to govern their activities (Haggerty & Ericson, 2006, p. 3).

Surveillance is viewed as an inherent characteristic, indeed a precondition, for the functioning of highly complex and organised societies: ‘In one form or another, it [surveillance] is a basic and ubiquitous social process, occurring in settings ranging from the family to state bureaucracies’ (Rule, 2007, p. 14). Authors point out that while the term surveillance often conjures up negative images, particularly since 9/11, when it became ‘popularly associated with crime and national security’ (Marx, 2005), the collection and use of personal information has long been a feature of society. Medical records, electoral rolls, credit cards, even library cards have been an integral part of daily life for many decades (Clarke, 2003; Fuchs, 2011; Lyon, 2002). These researchers argue that there are many positive benefits accruing from surveillance and note that in

most instances information gathering activities are neither covert nor detrimental and the vast majority of the population actively cooperate with and contribute to the collection of their personal information. Surveillance is therefore not inherently negative since ‘the same systems that may be feared for their power to keep track of personal lives are established to protect and enhance life-chances’ (Lyon, 2002, p. 4). However, while arguing that the collection and aggregation of personal data generally has positive benefits, or at the least is innocuous, these authors do acknowledge the ever-present potential for negative impacts (Clarke, 1998; Lyon, 2004; Peissl, 2003). Lyon summarises this perspective with his observation that the way in which data are used may have ‘genuine benefits and plausible rationales, but may also have palpable disadvantages. Surveillance is always Janus faced’ (Lyon, 2004, p. 164).

Approaching surveillance from this perspective highlights the complexities of information gathering practices. It points to the blurring of boundaries between consensual monitoring and non-consensual surveillance and the contextual aspect when determining the impact of many information gathering activities. Thus, the use of genetic material in the context of medical research may be considered appropriate, since it is perceived to have potential health benefits for individuals and the community. Yet collection of this information for genetic screening programs of new-born babies has been viewed as inappropriate and potentially harmful (Mariner, 2007). Similarly use of genetic material by the Western Australian police is accepted as appropriate by some, since it is being used in the interests of law enforcement and protection of the community, yet this same practice is viewed by others as inappropriate, an intrusion on civil liberties, and an example of function creep. For many, the use of genetic information by insurance companies or employers is inappropriate and potentially discriminatory yet it is currently legal in Australia for life insurers and employers to utilise this information, as long as they are able to justify their

actions. Highlighting this blurring of boundaries provides some insight into function creep, showing how consensual information gathering can move to surveillance almost unnoticed or uncontested.

These broad analyses of surveillance activities encourage a critique of consensual monitoring programs and practices. Applying this critical perspective to health environment identifies the potential for coercion and/or unintended consequences in programs ranging from genetic screening of newborns (Mariner, 2007), to proposed mental health checks on Australian three-year-olds (Butler, 2012), to calls for mandatory HIV tests for sex workers (Scarlet Alliance, 2007). Broad-ranging analyses also identify coercive practices embedded in ostensibly beneficial programs such as the 2010 Australian Bureau of Statistics health survey which aimed to establish benchmarks for future health strategies (Australian Bureau of Statistics, 2010). Individuals who refused to participate in this survey were liable for fines (Dunleavy, 2010). In another example the Federal Labor government proposed to link childhood immunisation to the Family Tax Benefit. Leake argues that, 'children who already miss out by not being immunised may be further disadvantaged through economic disparities' (cited in Sweet, 2011).

Neutral analyses of surveillance challenge the top-down, hierarchical model of power implied by the panoptic metaphor. Instead, they represent surveillance networks as decentralised, non-hierarchical and multi-directional. These discussions emphasise the existence of multiple goals, the potential for both reciprocal and non-reciprocal surveillance and the possibility for resistance to surveillance. Everyone has the opportunity to observe and the opportunity to participate in, or resist surveillance (Allmer, 2011; Lyon, 2004; Peissl, 2003; Staples, 2000). Studies of health monitoring systems illustrate these differentials. Home monitoring systems are designed to enable disabled, ill or ageing individuals to remain living independently. While some studies point to

these technologies being viewed as an intrusion into what has traditionally been considered the private sphere, others point to patients perceiving ongoing surveillance as empowering (Cantor, 2006; Essen, 2008; Hughes & Louw, 2002). Essen argues that these findings challenge the generally accepted roles ascribed to the agents and targets of surveillance (2008).

Despite the insights and research directions offered by this broad understanding of surveillance, the approach has been criticised. Critics argue it masks power differentials inherent in information gathering practices, focuses on technology to the detriment of social aspects of surveillance and normalises surveillance which potentially trivialising concerns. In seeking to counter the panoptic *surveillance-as-domination* representation of power, it is suggested that this more encompassing approach masks the asymmetrical distribution of power which can enable governments and corporations to more effectively achieve their goals while making it difficult for the less powerful to resist. In addition, incorporating monitoring and surveillance activities within the one definition paves the way for trivialising coercive forms of surveillance: 'If everything is surveillance, it becomes difficult to criticize repressive forms of surveillance politically because surveillance is then a term that is used in everyday language' (Fuchs, 2011, p. 126). In public health, the term surveillance is routinely used in discussions to describe a wide range of health-related monitoring activities. This has seen surveillance come to be associated with positive goals making the moves to non-consensual information gathering and surveillance appear less threatening, particularly when justified in positive terms. Allmer (2011) also suggests that this perspective focuses on technology and the technical aspects of personal information collection and surveillance. A focus on surveillance systems deflects attention from the 'cultural circuitries in which surveillance systems are embedded' (Smith, 2012). While these social dimensions are not ignored, they tend to be explored in the context of technical systems.

Notwithstanding these criticisms, this surveillance as neutral approach to exploring and understanding surveillance highlights the complexity of the health care environment with its multiple players and their complex, potentially competing goals and purposes for seeking access to information. Discussions acknowledge the positive benefits of information gathering while drawing attention to the possible dangers of some uses of personal information. The insights gained from this inclusive approach create an imperative for researchers to explore both positive and negative perceptions and experiences of surveillance.

2.3.4 Privacy and surveillance

Surveillance literature can also be approached through discussions about the relevance of privacy as a concept for analysing surveillance and information gathering practices. The discussion is broadly differentiated between those who argue that privacy is an inadequate concept for dealing with the complexity and scope of contemporary surveillance practices (Crompton, 2001; Gilliom, 2011; Stalder, 2011), and those who argue that privacy, while it has limitations, remains a central and useful concept (Bennett, 2011; Regan, 2011). In recent editions of the *Surveillance Society* journal, the discussion is represented as a debate, but it may more accurately be understood as alternative responses to the acknowledged shortcomings of the concept of privacy as an analytical tool. Bennett (2011, p. 485) indicates this in his comment that ‘there is one issue over which this broad and diverse community of surveillance scholars tends to agree: the concept of privacy and the policies it generates are inadequate.’ Discussions about these perceived inadequacies are complex, diverse, sometimes overlapping, but not always conflicting. The discussions primarily focus on the use of the concept for theoretical analyses rather than for application in researching information gathering practices. This is evident in Bennett’s comment that he was interested in ‘what surveillance scholars think the concept means given that those understandings animate particular critiques

and reformulations’ (2011, p. 486). The discussion/debate points to the various constructions of privacy, surveillance and information use that potentially influence policy development and regulatory frameworks in Australia. Of particular interest to this study are critiques about the conceptualisations of privacy itself, and discussion about the relevance of this concept for explaining and managing surveillance activity.

There is broad agreement within surveillance literature that the concept of privacy, as it is used in policy and other regulatory mechanisms, is linked to ‘individualism and notions of separation between the state and civil society’ (Bennett, 2011, p. 486). Privacy is represented as a means to protect the individual from interference or intrusive activity by society, institutions or other individuals. This creates a perceived dichotomy between public and private underpinning many information management initiatives (Bennett, 2011; Henman & Marston, 2008; Regan, 2011). Critics of this construct argue that the dichotomy between private and public places the individual’s right to privacy in conflict with collective need, the common good, and similar community-based values and interests, making privacy vulnerable to erosion:

Privacy is a weak argument in the face of overwhelming arguments for public safety, drug-control, accountability and welfare fraud control; privacy has, for the most part, become a procedural order, not a substantive guarantee: if the rules are followed (consent forms, warrants, boilerplate notifications) then the objections are null (Gilliom, 2011, p. 503).

Critics also suggest that this individualistic construct deflects attention away from the systematic disadvantaging of whole populations that may be a consequence of contemporary surveillance practices. This is acknowledged by both those who support privacy as a central concept and by those who argue against it. However, responses to the perceived shortcoming differ. Bennett (2011, p. 488), in his defence of privacy argues that the criticism is directed at an out-dated conception of privacy and that collective conceptions of privacy

are now being incorporated into the discourse. There is some evidence to support this, as various scholars emphasise the need to broaden privacy to incorporate concepts such as group privacy, social justice, and democratic participation (Jacob, 2006; Juntti & Turnpenny, 2009; Lyon, 2007c; Shaw & Greenhalgh, 2008). Helen Nissenbaum (2010) also challenges the public/privacy dichotomy in the legal context, arguing that the issue 'is not simply about restricting the flow of information but ensuring that it flows appropriately' (2010 p. 2). She argues that appropriateness is determined by 'considering the social, political or historical contexts of its proposed use' (2010, p. 127). Gilliom on the other hand, argues that regardless of this trend, privacy continues to have an individualist focus that is inadequate for analysing contemporary surveillance practices: 'These concerns cannot be solved with a few upgrades' (2011, p. 501).

The critique of the concept translates into a discussion about the efficacy of privacy for understanding broader issues of surveillance and surveillance practices (Bennett, 2011; Gilliom, 2011). Thus, the privacy/public interest dichotomy is argued to be too simplistic to apply to the complex, multi-directional relationships that characterise modern surveillance practices (Gilliom, 2011; Regan, 2011). The individualistic construct of privacy is also considered inadequate for exploring systemic surveillance: 'the scale and scope of surveillance and information gathering problems exist at a systemic level (institutions, social practices, fabric of modern life), not at the level of private space' (Regan, 2007, p. 497). Therefore, as a theoretical concept, privacy is applicable for exploring only some of the wide-ranging issues and concerns explored by surveillance scholars. It is 'too narrow to catch the richness of the surveillance experience' (Gilliom, 2011, p. 501).

The effectiveness of a privacy regime in its practical role of protecting individuals and the community from surveillance is also an area of contention.

Bennett, applying his theoretical argument that privacy as a concept has expanded beyond its individualistic construct, argues that where policy development is concerned, 'the privacy value has been reframed at a governance level to meet the collective challenges posed by the broadening and deepening of surveillance,' (2011, p. 486). Critics respond with the observation that legislative and policy initiatives based on privacy have done little to constrain expanding surveillance activities and collection of massive amounts of personal information by governments and corporations (Gilliom, 2011). Bennett, who supports privacy as a central construct for understanding surveillance, does agree with this criticism:

Contemporary information privacy legislation is often designed to manage the processing of personal data, rather than to limit it. From the perspective of those interested in understanding and curtailing excessive surveillance, the formulation of the privacy problem in terms of trying to strike the right 'balance' between privacy and organizational demands for personal information does not address the deeper issue and cannot halt surveillance (Bennett, 2011, p. 494).

At the same time, Bennett continues to argue that privacy remains a useful tool for forcing organisations to abide by agreed protocols for use of personal information. Regan supports this view, seeking to integrate privacy and surveillance so that problems are best defined in terms of surveillance but 'the social and individual value that is at risk from surveillance is still best captured by privacy' (2011, p. 497). Despite being presented as a debate, both sides agree that the privacy/public interest dichotomy does not adequately address the issues around contemporary information gathering and surveillance practices.

2.3.5 Useful explanations?

Historical perspectives link expanding surveillance practices to the increasing reliance of governments and corporations on personal information, thereby highlighting an inherent contradiction between expectations that the state will

safeguard individual privacy while legitimating the use of personal information for an expanding range of activities. This suggests that function creep may be almost inevitable and that despite regular review and modification of legislation, policies and protocols, access to personal information will continue to expand: 'There are more privacy rules, and less privacy' (Rule 2008, cited in Bennett, 2011, p. 494). While providing an explanation for function creep, historical perspectives are too broad to allow exploration of the particular social processes and relations that support it. The typological approaches to exploring surveillance supplement insights offered by historical perspectives. Generally, studies adopting a neutral definition of surveillance point to the complexity of surveillance practices while studies adopting the negative perspective highlight the negative connotations of surveillance and allow a focus on issues of power, conflict, and social control. Neither perspective adequately explores issues of power and control in shaping the understandings that allow expanding function creep and surveillance. Discussions exploring privacy as an adequate concept for understanding and managing surveillance circle around the issue, but again provide no theoretical guidance.

Analyses adopting a neutral, inclusive definition of surveillance highlight the ambiguity of surveillance activities, the blurring of boundaries between consensual monitoring and non-consensual surveillance and the need to consider context when exploring the impact of surveillance. These analyses demonstrate that function creep often occurs incrementally and opportunistically:

Here, a tool introduced for a specific purpose comes to be used for other purposes, as those with technology realise its potential and ask 'why not?' It is an easy (and slippery in several senses) move from consensual monitoring to non-consensual activities (Marx, 2005, p. 386).

However, while these studies explore the complexity of surveillance practices, their representation of surveillance as 'a plural, neutral and technical process'

(Allmer, 2011, p. 573) is limiting, particularly for this study which seeks to explore issues of power and control in surveillance and information gathering practices.

By excluding but not denying positive monitoring activities, discussions defining surveillance as a negative concept supplement the insights gained from the neutral perspective. Insights offered by this perspective direct the focus of analyses to issues of power, conflict, and control. Yet as noted, the reliance on the panoptic metaphor to explore surveillance is considered a limitation: 'there is a distinction, a limitation or way in which Foucault's model does not completely fit the contemporary, global, technological or political dynamics of surveillance' (Lyon, 2006, p. 26). Despite criticisms, the panoptic metaphor and its various permutations continue to influence surveillance studies (Fuchs, 2011; Gallagher, 2010).

Lyon observes that the various strands of surveillance theory 'make considerable strides in helping to explain why [it] is so important to modernity' (2001a, p. 124). At the same time, each theoretical strand, when considered independently, provides only part of the picture. A multi-faceted approach, drawing on the different theoretical strands provides a more comprehensive analysis of the scope, complexity and consequences of expanding uses of personal information in contemporary society (Pecora, 2002; Lyon, 1994; Haggerty and Ericson, 2006; Levi and Wall, 2004; Jenness et al., 2007; McCahill, 2007).

While informative, surveillance studies focus primarily on describing the processes and consequences of expanding uses of personal information. This study is concerned with the exercise of power and control in constructing the understandings that facilitate expanding uses of personal information and associated surveillance practices, which are not generally addressed in the

surveillance literature. Therefore, while drawing on the insights from surveillance literature this study moves beyond the parameters of that discussion. In doing so, it draws more comprehensively on the work of Michel Foucault.

2.3.6 Foucault: beyond surveillance studies

As noted, the use of Foucault's panoptic metaphor to explain surveillance has been the subject of criticism. The criticism points to perceived limitations in the applicability of Foucault's metaphor to the contemporary information gathering environment. Lyon summarises the criticism: 'there is a distinction, a limitation or way in which Foucault's model does not completely fit the contemporary, global, technological or political dynamics of surveillance' (2006, p. 26). However, while these criticisms may apply to the way the metaphor is applied in surveillance literature, Rose argues that such criticisms are based on a 'sociological misreading of Foucault' (1999, p. 273). This study suggests that this misreading is a consequence, at least in part, of adopting aspects of Foucault's work without linking them to his broader conceptualisation of modern power and its relationship to knowledge and discourse. As Lyon suggests, this results in 'a fairly un-Foucauldian version of the panopticon' (2004, p. 334). Gallagher argues that 'there is a clear consensus amongst Foucault scholars that his account of the Panopticon is most useful if it is understood as an ideal model of power, rather than as a description of how specific institutions actually function' (Gallagher, 2010, p. 262). Surveillance studies generally do not use the panopticon in this way, but instead tend to fit the metaphor 'into existing analyses of discipline and social control without the baggage of discourse' (Lyon in Webster, 2004, p. 334). Marx argues that the focus on the panopticon without consideration of the discourses that contribute to their power 'vulgarizes the complex and sometimes contradictory Foucauldian perspective. We need to counter and qualify a simple unreconstructed panoptic view' (2005, p. 368). This study seeks to do so by

moving beyond the hierarchical, centralised representation of the panopticon as it appears in surveillance literature to locate the concept within Foucault's analysis of modern power and its relationship to knowledge and discourse. This study uses Foucault's work to provide a theoretical and methodological framework, enabling an exploration of the interaction between discourses within the academic discipline of health informatics, the Australian privacy framework and broader surveillance practices and function creep. The next section of this chapter discusses Foucault's arguments about the relationship between power, knowledge and discourse, explicating the relevance of his work for this study.

2.4 Foucault: Power, knowledge and discourse

Both surveillance scholars and Michel Foucault link surveillance and expanding use of personal information to modern society. Surveillance scholars represent these practices as an inherent characteristic of highly complex and organised societies, while Foucault viewed surveillance and the use of personal information as strategies that support the exercise of modern power. While surveillance studies focus on surveillance practices and processes, Foucault incorporates these as elements in his analysis of the relationship between power, knowledge, and discourse. It is this relationship that suggests the inevitability of function creep while offering an explanation for the acquiescence, even willing participation of the community in the process. His work also emphasises the possibility for resistance to these practices.

2.4.1 Modern power

In his discussions about power, Foucault focuses on how modern power is exercised: 'not in the sense of "How does it manifest itself?" but "By what means is it exercised?" and "What happens when individuals exert (as they say) power over others?"' (Foucault, in Dreyfus & Rabinow, 1983, p. 786). This is to emphasise his argument that power is not possessed but rather, is exercised in a complex, multi-directional network of relationships:

Power must be analysed as something which circulates, which only functions in the form of a chain. It is never localised here or there, never in anybody's hands, never appropriated as a commodity or piece of wealth. Power is employed and exercised through a net-like organisation (Foucault, 1980, p. 98).

Foucault also emphasises that 'power is not simply a relationship between partners, individual or collective; it is a way in which certain actions modify others' (Foucault in Dreyfus & Rabinow, 1983, p. 788). Power consists of two dimensions, anatomo-politics, or disciplinary power and biopolitics, the governance of populations. Foucault explains that these two poles of power represent a network 'whose highest function was perhaps no longer to kill, but to invest life through and through' (1978, p. 139). In stating this, Foucault is emphasising that his understanding of power is not negative. It is essentially productive and integral to modern society. Modern power is 'a fundamental instrument in the constitution of industrial capitalism and the type of society that is its accompaniment. It ensures the willing participation of citizens in the development of efficient economic systems' (1978, p. 104-106). The concept of healthism explains the connection between optimisation of individual capacity and the goals of capitalism: Healthism links 'public objectives for the good health and good order of the social body with the desire of individuals for health and well-being' (Rose, 1999, p. 74). Rather than being threatened or cajoled, individuals are treated on the assumption that they want to be healthy and are encouraged to behave in ways most likely to promote their own health: 'By adhering to the principles of healthism, our personal goals are aligned with political goals and we are thus rendered governable' (Rose, 1999, pp. 86-87). Disciplinary power seeks to regulate the behaviour of individuals through the application of complex systems of surveillance.

2.4.2 Disciplinary power

Disciplinary power flows through social institutions such as schools, hospitals, workplaces, and prisons. It operates continuously in the most ordinary of daily interactions: 'It applies itself to immediate everyday life' (Foucault, in Dreyfus

& Rabinow, 1983, p. 781). Its focus is on the individual and its purpose is 'to persuade the individual to conform to required standards' (Foucault, 1991, p. 174). Disciplinary power is exercised through the technologies of hierarchical observation, normative judgement, and examination. Surveillance and the collection of personal information are integral elements of these technologies. Hierarchical observation is based on the assumption that people can be controlled simply by observing them. It further assumes that control can be effective if people believe that they are being watched:

The exercise of discipline presupposes a mechanism that coerces by means of observation; an apparatus in which the techniques that make it possible to see induce the techniques of power and conversely, the means of coercion, make those on whom they are applied clearly visible' (Foucault, 1991, p. 170).

Foucault introduced the panoptic metaphor to explain how hierarchical observation operates. The panopticon, with its central watchtower surrounded by prisoner cells, allows enables individuals to be observed at all times while they themselves are unable to see the observers. They are therefore never sure when they are being observed. This uncertainty both controls their behaviour and encourages them to internalise surveillance. This results in self-monitoring and self-discipline where individuals will, of their own accord, alter their behaviour in accordance with what is expected of them.

You have a system of surveillance, which involves very little expense. Just a gaze which each individual under its weight will end by interiorisation to the point that he is his own overseer, each individual exercising this surveillance over and against himself (Foucault, 1980, p. 147)

While Foucault represents the panoptic relationship as hierarchical, he argues that it is not a one-way hierarchy. It can be reversed. The observer can become the observed: 'This panopticon, subtly arranged so that an observer may observe at a glance so many different individuals, also enables everyone to

come and observe any of the observers' (Foucault, 1991, p. 207). Thus, while a health organisation may be structured to create an all-encompassing panoptic gaze, at different times and in different contexts, consumers, health professionals, administrators and managers are able to monitor and control one another. Foucault did not apply the panoptic metaphor only to physical environments: 'it is not that the individuals who are members of disciplinary societies set about assembling in barracks, schools or prisons; rather an increasingly better invigilated process of adjustment has been sought after between productivities, resources of communication and the play of power relations' (in Dreyfus & Rabinow, 1983, p. 788). Consequently: 'one sees the spread of disciplinary procedures, not in the form of enclosed institutions, but as centres of observation disseminated throughout society' (Foucault, 1991, p. 212). Foucault thus uses the metaphor not to represent surveillance as centralised and hierarchical, but to emphasise the pervasiveness, multi-directional and invisible nature of modern disciplinary power: 'It is a generalizable model of functioning; a way of defining power relations in terms of the everyday life of men' (Foucault, 1995, p. 205, cited in Rabinow, 1991, p. 18).

Hierarchical observation enables the application of the technique of normative judgment. Rabinow explains that by normalization, Foucault means 'a system or finely graduated and measurable intervals in which individuals can be distributed around a norm' (1991, p. 20). Hierarchical observation is the means by which the information that allows the development and application of these norms of behaviour is collected. Normative judgment is formative rather than punitive: 'it has the function of reducing gaps. It must therefore be essentially corrective. Of all the penances, the most advantageous derive from the means of advancing their progress, by correcting their defects, and avoiding as much as possible punishment' (Foucault, 1991, p. 179). Individuals strive to reach the norms not because they are compelled to, but because it is normal to do so, and

to fail to do so would be abnormal. The desire to conform is evident in the willingness of professional groups to discipline their own and their colleagues' behaviour:

Surveillance operates through nurses being responsible not only for their own practice, but also for that of others. This calls for vigilance as to the extent to which colleagues are fit to practise (NMC 2004) and willingness to report concerns about their conduct, health or competence if necessary (Gastaldo & Holmes, 1999, p. 233).

The examination brings together hierarchical observation and normative judgement. It allows individuals who do not conform to be identified and disciplined: 'the examination combines the techniques of an observing hierarchy and those of a normalizing judgment. It is a normalizing gaze, a surveillance that makes it possible to qualify, to classify and to punish' (Foucault, 1991, p. 184). The examination operates across the spectrum of human activity, from the formal accreditation processes of academic institutions to the physical and psychological examination of the clinical consultation, to audit processes and performance reviews of employees. However, as with the other technologies of disciplinary power, the examination should not be viewed only in negative terms. It may also be productive and persuasive: 'The dirty individual should be made clean; the pregnant adolescent should have information on contraception; the fat man should be helped to adopt a healthier diet' (Gastaldo & Holmes, 1999, p. 235). In his earlier work, Foucault described disciplinary power as localised, dispersed and diffused throughout society. In his later work he discussed power as coalescing into a regulatory society wide network. At this point he introduced the concept of biopolitics.

2.4.3 Biopolitics

While the focus of disciplinary power is on micro-level control of the individual, biopolitics extends the technologies of modern power to the overall

management of populations. Biopower focusses on managing populations, and is exercised through 'the ensemble formed by the institutions, procedures, analyses and reflections, the calculations and tactics that allow the exercise of this very specific albeit complex form of power' (Foucault cited by Burchell et al., 1991, p. 102). This form of power is regulatory rather than disciplinary.

He viewed the social sciences as integral to the exercise of biopower. New disciplines like public health collect data, develop statistical analyses and probabilities and produce norms and guidelines on a broad spectrum of human behaviour. These norms and guidelines are used to promulgate a range of policies that seek to govern the way people live their lives. This is a subtle and positive process rather than a negative one: 'it seeks to exert a positive influence on life. It endeavours to administer, optimise and multiply it, subjecting it to precise controls and comprehensive regulations' (Foucault, 1978, p. 137). The effective exercise of biopower sees individuals taking an active role in monitoring and controlling their own behaviour. The concept of the *risky self* explicates the links between the social sciences, personal health information and biopower. The risky self arose from the combination of increased efficacy of medical testing with the emergence of risk factor epidemiology. Risk factor epidemiology involves the collection and analysis of the large amounts of data to identify causal links between risk factors, lifestyles and life expectancy. This knowledge is used to control individual behaviour. Increasingly, individuals voluntarily restrict their behaviour in order to care for their health even when they are experiencing well-being. This has seen individuals voluntarily undergoing techniques such as preventative mastectomies (Vaz & Bruno, 2003, p. 281). The social sciences, while claiming to provide insights into human social existence, also operate to control behaviour and discipline those who do not conform (Gastaldo & Holmes, 1999).

While his representation of modern power may be interpreted as repressive, Foucault argues that this is not the case. The exercise of modern power may be positive and productive: ‘do not concentrate on the study of the punitive mechanisms on their repressive effects alone but situate them in a whole series of their possible positive effects’ (Foucault, 1991, p. 23). Foucault further argues that there is always the opportunity to resist the exercise of power because power can only be exercised over free subjects: ‘By this we mean individual or collective subjects who are faced with a field of possibilities in which several ways of behaving, several reactions and diverse comportments may be realised’ (in Dreyfus & Rabinow, 1983, p. 790). Resistance itself is the exercise power: ‘it would not be possible for power relations to exist without points of insubordination which, by definition, are the means of escape’ (in Dreyfus & Rabinow, 1983, p. 794).

2.4.4 Personal health information and modern power

Foucault’s work provides a theoretical context for exploring the increasing and widespread secondary uses of personal health information. While generally explained and justified in terms of providing quality care, increasing efficiency, and increasing consumer health and well-being, the practices of contemporary health care may also be understood as part of the network of modern power. Surveillance and the collection of personal health information are fundamental to these practices. Lupton suggests that ‘from the Foucauldian perspective, power as it operates in the medical encounter is a disciplinary power that provides guidelines about how patients should understand, regulate and experience their bodies’ (cited in Earle et al., 2009, p. 21). The exercise of disciplinary power is most evident in clinical encounters, but public health programs extend disciplinary power into almost all areas of daily life. This expansion is facilitating self-surveillance as an expanding range of systems and processes enable individuals to test themselves and record the results for others to peruse. At the same time, Gilbert notes, ‘patients may be self-managing, but they still have to report to healthcare professionals for guidance, advice,

monitoring and treatment' (2003, p. 40). Self-surveillance is supplemented by ongoing hierarchical observation which identifies individuals needing remedial guidance and advice. Disciplinary power also operates to control the behaviour of health professionals and management. The use of accreditation procedures, performance measures and quality standards may be understood as tools for normative judgement. While represented as initiatives designed to improve clinical practice, raise the quality of care and provide efficiencies in service delivery, they may also be understood as strategies to monitor, measure and control the activities of health professionals (Gilbert, 2003; Gastaldo & Holmes, 1999; Ferlie et al., 2012). Witherik et al. explain:

Clinical governance can be interpreted as a specific example of 'governmentality' in practice: medical professional expertise is an essential aspect of the management of health risks, but its regulation requires that clinicians engage in their own surveillance and 'self-management' (Witherik et al. undated)

Bauer and Olsen (2009) illustrate the use of personal health information to facilitate control in the area of public health. They point to increasingly sophisticated electronic systems used to link clinical records, disease registers, demographic data, environmental surveillance data, and indices of socio-economic disadvantage to 'render visible patterns of population health' (Bauer & Olsen, 2009, p. 122). On the basis of this information, education programs are developed to encourage individuals to adjust their diet, exercise regularly, immunise their children, apply appropriate hygiene standards and engage in safe sex practices. Personal health information forms the basis of these systems of monitoring and control: 'Individual patient data has become an integral part of a system of prudential oversight and quality review; medical professional expertise is an essential aspect of the management of health risks' (Magnusson, 2004, p. 686).

Foucault's discussion of disciplinary power and governance enhance discussions within surveillance literature. Representing secondary use of personal health information and surveillance as strategies of modern power enables links to be made between these activities and issues of power, control and discrimination. However, while these discussions point to the willingness of individuals, groups, and populations to accept the imposition of standards, norms, expectations and performance indicators, they do not adequately explain why they do so. Foucault's representation of the relationship between power and knowledge, expressed through discourse provides this understanding.

2.4.5 Power/knowledge/discourse

Foucault views power and knowledge as intimately connected. 'We are subjected to the production of truth through power and we cannot exercise power except through the production of truth' (Foucault, 1980, p. 93). Thus, knowledge is the basis for the exercise of power, while power underpins the production of knowledge. Medical professionals control clinical care because they are perceived to have knowledge about health and illness that the wider population does not have. At the same time, medical professionals are able to use their position as experts to shape the production of knowledge about health and illness. Thus, they use the language of science and technology to shape knowledge about health and disease in terms of viruses, bacteria and infections. Foucault argues that knowledge is power over others, the power to define others. Knowledge therefore becomes 'a mode of surveillance, regulation, discipline' (Sarup, 1993, p. 67).

With this argument, Foucault challenges the neutrality of knowledge creation. He argues that in any particular historical period, knowledge and the way it is dealt with, is a result of power relations that allow certain knowledge and knowledge practices to emerge while rejecting or ignoring others. 'Perhaps we should abandon a whole tradition that allows us to imagine that knowledge can

only exist where the power relations are suspended and that knowledge can develop only outside its injunctions, its demands and its interests' (Foucault, cited in Dreyfus & Rabinow, 1983, p. 27). A change in the social and political context results in different knowledge and knowledge creation practices emerging.

These ideas can be applied to the use of personal health information to argue that acknowledged experts, including information management professionals, privacy experts, and health professionals, control the development of frameworks and systems to manage the collection and use of personal health information because they are perceived to have expertise that the wider population does not have. This claim to expert knowledge enables these groups to exercise power to shape the way the issues are understood and to determine appropriate strategies to manage them. In doing so, these experts increase their legitimacy, whilst others are silenced and de-legitimised (Biggs, & Powell, 2001).

Discourse is a key component in this power/knowledge nexus. It is through discourse that the production of knowledge takes place and through which power is exercised and power relations are maintained. However, the concept, as used by Foucault, is difficult to define. He himself observes that 'instead of gradually reducing the rather fluctuating meaning of the word discourse, I believe I have, in fact, added to its meanings: treating it sometimes as the general domain of all statements, sometimes as an individualizable group of statements, and sometimes as a regulated practice that accounts for a number of statements' (1972:80). Within this complex of understandings, O'Farrell (2007) points out that in *Archaeology of Knowledge*, Foucault also referred to discourse as 'a certain way of speaking' (1972, p. 193). This points to language and language patterns as elements of discourse. However a Foucauldian perspective views discourse as much more than language. Discourses act at a

constitutive level as social practices and in so doing, 'form the objects of which they speak' (Foucault, 1972, p. 87). Social practices can range from forms of address to ways of communicating to the design of buildings. Social practices of privileged discourses are institutionally supported. The discourse which constructs use of personal information as a privacy/public interest balance is supported by institutionalised social practices across a network of education and research institutions, legal and government instrumentalities, government regulation and funding systems, public and private health care and insurance organisations, the media and commercial organisations. The Australian privacy framework is part of these institutional practices.

Discourses also form subjects that are related to one another in a structure of authority and control that determines who can speak, what they can say, and how much authority they have. 'A discourse ascribes to duly certified specialists the right to speak with authority and it tacitly includes in this chosen group only those individuals who share certain assumptions' (Foucault., 1972, p. 46). Within the discourse supporting health information management, subjects may be information management professionals, legal and human rights experts, privacy advocates and consumers. Authority to speak is conferred via qualifications, profession, and status position in the network of power/knowledge. Those occupying the position of privacy expert, or information management expert may be viewed as possessing legitimate knowledge, and accorded the authority to pronounce on matters of personal information use. Included in this group are only those individuals who share assumptions about personal health information issues and who have completed the required education and accreditation practices. Consumers may occupy subject positions and be expected to accept guidance from the expert. Foucault emphasised that subjects do not initiate discourse, but 'are simultaneously the products of discourse and a means by which discourses are propagated' (James, 2004, p. 17).

Discourses differ from one another in the kinds of facts they legitimise, and what kinds of meanings are absent or ignored. Clearly, a discourse does not represent all knowledge. It represents one particular view or position. Several more or less conflicting discourses may exist simultaneously in particular fields of knowledge, or in a particular institution at a certain point in time. Of these, one may become privileged, achieving the authority of *truth*, while others become marginalised: ‘In our society, certain discourses, certain forms of knowledge, are clearly privileged over others: the medico-scientific discourse of psychiatry over the “unreasoned” discourse of mad, the objective discourse of law over the “self-interested” discourse of criminals’ (Foucault, 1972, p. 26). At the same time every discourse remains in competition with alternative discourses. There is always the potential for change in the hierarchy of privilege and marginalisation. This brings up the question raised by Foucault himself of ‘why, at a given time, out of all the possible things that could be said, only certain things were said: How is it that one particular statement appeared rather than another’ (Foucault, 1972, p. 27).

2.4.6 Claim-making sites

From a Foucauldian perspective, ‘claim-making institutions such as the media, government and science judge negotiate and define the nature of problems and present them to the lay public accordingly’ (Hannigan, 1995). This study argues that the representation of personal information management as a privacy/public interest balance is defined and negotiated within social institutions such as governments and their instrumentalities, public bodies and academic institutions. This process begins in local contexts, including university faculties and departments. More influential discourses coalesce and integrate as they are taken up by broader social institutions. The discourse, or discourses that become dominant shape the privacy framework, and in doing so, support and reflects existing power relations. The health informatics community, with its

ability to influence both the development of information management systems and the way these systems are used, may be regarded as one such claim-making site. The community claims significant responsibility for both the discipline and the profession, contributing to the production of the health informatics academic knowledge base, shaping the education and accreditation of health informatics professionals and providing high-level expert advice to government health care organisations and other groups regarding laws, policies, strategies, systems and protocols governing the use of health information. The Australian College of Health Informatics, a peak body of the health informatics community, states that:

ACHI has the expertise to advise government and the professions on eHealth matters, in particular the national direction, implementation and support for health informatics and educational and capacity building, innovation and diffusion, standards development, research, performance and quality management (ACHI, 2009).

Since it is in a position to influence both the types of information management systems that are developed and the way they are used, the health informatics community is strategically located to be able to either support or resist initiatives for proposed expanded uses of personal health information in Australia. This potential is emphasised by Foucault's views that academic disciplines are particularly powerful discourses.

2.5 The power of academic disciplines

Foucault argues that in order to know how to manage people, 'human beings had to become the subject of scientific enquiry' (Rutherford, 1999, p. 38). In making this observation, he links modern power to the rise of the social sciences, arguing that it is the proliferation of statistical knowledge about the human social condition produced by the social sciences that supports the management and control of both individuals and populations. Quantification of phenomena such as birth-rates, longevity, fertility, patterns of diet and

habitation, facilitates the establishment of the norms and standards that are used to encourage conformity and to identify and suppress abnormality. Thus, for Foucault, the social sciences, while claiming to provide insights into human social existence, are discourses of power which aim to control behaviour and discipline those who do not conform: 'The formal knowledge complexes (science, social sciences, statistics) in particular have come to inform techniques of power in the modern world' (Stevenson & Cutcliffe, 2006, p. 718). The focal point for knowledge development within the social sciences is the formal institutional complex of academic disciplines. An academic discipline is a particularly powerful form of discourse since it is able to impose conformity about what knowledge is valid, how it is acquired, and how it is shared and used without recourse to external authorities (Lillis, 1997; Woodward-Kron, 1999). This enables a dominant discourse to control core knowledge and skills, and oversee the training of new graduates, thus ensuring its domination. They are also, as Foucault argues, powerful in the wider power/knowledge structures. Thus, health informatics represents an important site for discourses about health information management.

2.5.1 Health Informatics: Competing discourses

Academic disciplines are generally represented as a unity of shared issues, themes and concepts where knowledge development is cumulative and integrating process. Foucault's work challenges this view. According to Palys, Foucault challenges the assumption that the production of knowledge is an ongoing and objective process 'other than in an incredibly trivial sense that we are on a time line and, as a species, are not immobile or stagnant' (1989). Palys argues that from a Foucauldian perspective knowledge development is piecemeal, local and ad hoc, resulting from social processes closely linked to the distribution of power and power relationships within particular discursive fields or disciplines. Thus, academic disciplines comprise multiple discourses and the creation of disciplinary knowledge is a struggle whereby one discourse

seeks to assert its truth claims over others. Although powerful, the accepted discourse represents only one possible knowledge and is always subject to challenge. Introna, in his discussion of the academic discipline of information systems, describes the process whereby more successful discourses garner the support to become institutionalised regimes of truth: 'If they succeed to build up a sustainable "intellectual" or "academic" infrastructure of departments, research programmes, conferences, journals, associations, etc., they may eventually become acknowledged as a discipline' (2003, p. 236). Introna draws attention to the political nature of this process: 'they are not a "discipline" because they got it right- found the distinctive core descriptions, theories, and methodologies- but because they have convinced enough people, and aligned themselves with enough people that matter' (2003, p. 236). Inherent in this is the understanding is that what is accepted as knowledge may change as power relations change. Therefore, within the discipline of health informatics, it can be argued that there is no one *true* body of knowledge to be discovered, but rather, multiple truths to be identified and explored.

2.5.2 Discourses in health informatics: Previous studies

A review of the literature found few discourse analyses within the field of health informatics. Those that were identified focus on specific applications of health informatics technologies such as telehealth or e-health rather than the broader knowledge development and dissemination processes of the academic discipline. These include a study by Klecun-Dabrowska & Cornford (2000) exploring the implications of different discourses of telehealth in policy in the United Kingdom, a study by Cornford & Klecun-Dabrowska (2003) describing the processes by which telehealth innovations 'acquire an identity' and a study by Greenhalgh et al. exploring telehealth discourses in the context of stakeholder perspectives. In the only Australian study located, Horsfield and Peterson (2000) also focus on telehealth, identifying discourses shaping the diffusion of telehealth across health services. Horsfield and Peterson identify

six discourses. These are a consumer discourse, a critical discourse, a pedagogic discourse, a medical practitioner discourse, an information technology as progress discourse, and a discourse of e-health as commerce (2000, pp. 8-10). Horsfield and Peterson conclude that, at the time of their study, e-health as commerce was the dominant discourse in Australia. They argue that the understanding of e-health within this discourse 'now functions in Australia as an all-encompassing label that refers not only to the use of IT in health care, but also to political, policy-driven, entrepreneurial and commercial enterprises in the health care field' (p. 10). While Horsfield and Peterson focus particularly on language in texts, this present study expands this to explore the social practices and relations associated with more influential health informatics discourses. While acknowledging limitations with regard to generalising the results of a discourse analysis (McHoul & Grace, 1993), some synergies between the Horsfield and Peterson study and this present study are noted and discussed in the chapters 6, 7 and 8.

2.6 Study questions

Foucault argues that the task of the researcher is to determine 'all the possible enunciations that could be made on a particular subject, why it was that particular statements emerged to the exclusion of all others' (Graham, 2011, p. 667). This focuses the analysis not on privacy per se, but on broader issues of power and control that have shaped the understanding of privacy and privacy protection (Jacobs, 2006; Lyon, 2007b; Bacchi, cited in Shaw & Greehalgh, 2008; Juntti & Turnpenny, 2009). This study sought to identify enunciations or discourses within the discipline of health informatics. In particular, it sought to identify the way the discourses constructed personal health information management issues and how these influenced the position adopted by the academic community and what might be the implications of this. The specific questions addressed were:

1. What discourses can be identified in the discipline of health informatics?
2. What is the relative influence of the discourses identified within the academic discipline?
3. How do these discourses construct issues around use of personal health information?
4. What might be the implications of this?

The next chapter describes the methodology used for the study.

Chapter 3: Research Design and Methodology

3.1 Introduction

This chapter describes the methodology, research design and methods used in the study. It begins by linking Foucault's theoretical approach to the discourse methodology adopted for the study, explaining how this methodology or 'tool-box' as Foucault called it (1972, p. 523) was implemented. The discussion describes the three phases of the study, explaining the purpose of each phase, the texts or data that were analysed and the specific methods used. The final section of the chapter discusses limitations of the methodological approach.

3.1.1 Methodology

The study is located within the broader social constructionist approach to understanding and explaining the social world. Social constructionists seek to uncover the ways different understandings of social reality both construct and constrain the way individuals and groups act and interact. The task of the researcher is to analyse the way these understandings are created, institutionalised, sustained, and shared (Dreyfus & Rabinow 1983). This study explored issues of power and control in shaping understandings about information use in the Australian privacy framework. It focussed specifically on the academic discipline of health informatics as a key claim-making site for shaping these understandings. It drew on the work of Michel Foucault to provide a theoretical framework. This theoretical framework and the questions arising from it pointed to discourse analysis as the most appropriate methodology.

Approaches to discourse analysis may be differentiated along a number of dimensions including disciplinary origin, purpose, and particular interpretation of the interaction between language, power and the social world. Morgan (2010) identifies six approaches. These range from conversation analyses

focusing on patterns within language itself, to interactional sociolinguistics exploring the way language constructs psychological phenomena, to critical discourse analyses and Foucauldian discourse analyses which are more concerned with the interaction between language and the social world. Wetherall observes that 'the kind of discourse research which is favoured for a particular project involves a complex balancing act between the type of data one wants to collect, the topic, and the discourse tradition which seems appropriate' (2001, p. 380). This suggested either a Foucauldian or a critical discourse analysis as the most appropriate approach. The study was premised on Foucault's theoretical perspective that a discipline is 'not the sum total of all the truths that may be uttered concerning something' (Foucault, 1972, p. 223). Instead, a discipline comprises 'discontinuous practices, which cross each other, are sometimes juxtaposed with one another, but can just as well exclude or be aware of each other' (Foucault, cited in Young, 1981, p. 67). The study sought to identify these discontinuities within the academic discipline of health informatics. This required a methodological framework that looked beneath ontological and epistemological assumptions about knowledge and knowledge development to identify the plurality of discourses and their interaction over time. This allowed the study to challenge the understandings constructed by the discourses. However, rather than having the more overtly political goal of critical discourse analysis which is to 'understand, expose, and resist social inequality' (van Dijk, 2001, p.352), this study was primarily concerned with describing the discourses and their interaction in the production of health informatics knowledge. Therefore, a Foucauldian methodology was considered more appropriate since with this approach 'the role of critique is less pointed: the purpose is to reveal, rather than emancipate' (McGregor, 2004). Such a methodology is exploratory, explanatory and descriptive.

3.1.2 Using Foucault's tool-box

Adopting a Foucauldian influenced methodology presents challenges since, over the period of his writing, Foucault 'shifted his points of view and angles of attack and subject matter, structurally and philosophically' (O'Farrell, 2005, p. 73). Since his work can appear contradictory, it can be difficult to determine which of his writings is most relevant or appropriate. A further challenge relates to the lack of detail in his writing about methods and strategies for undertaking a discourse analysis. The secondary literature generally agrees that neither Foucault's methodology nor his methods are overly well prescribed (Burchell et al., 1991; Hook, 2005; Kendall & Wickham, 1999; O'Farrell, 2005). These challenges lead many who draw on his work to begin by referring to his oft-quoted comment that 'I would like my books to be a kind of tool-box which others can rummage through to find a tool which they can use however they wish in their own area' (Foucault, 1972, p. 523). Since Foucault provides a number of broad guidelines and principles, but does not espouse specific strategies for undertaking a discourse analysis, rummaging through the tool-box is not straightforward. This is indicated by the diverse views, discussion, debate and critique in the secondary literature (Hook, 2001; Jacobs, 2006; O'Farrell, 2005; Soyland & Kendall, 1997). Graham suggests that since Foucault's purpose is to challenge the claims of science as the objective pursuit of knowledge and truth, he 'necessarily rejected any suggestion of prescriptive methodologies' (2005, p. 2). Graham also suggests that a lack of methodological detail on the part of many researchers may be 'intended to ensure consistency with Foucault's approach and to minimise accusations of prescriptive methodology/methods, or of making truth claims through the imposition of precise methodologies' (Graham, 2005, p. 2). More severe critics argue that many studies claiming to use Foucauldian methods 'bear little resemblance to the original' (Soyland & Kendall, 1997, p. 9), and are in fact 'erroneous applications' of Foucault's concept of discourse (Hook, 2001, p. 522). These criticisms may explain, at least in part, the reticence of many

researchers adopting a Foucauldian approach to expand upon the methodological details of their studies (Graham, 2005). Yet as Jacobs observes, 'if discourse analysis is to be valued, it will be incumbent on researchers to be explicit about the techniques employed' (2006, p. 42). This chapter is intended to fulfil this requirement despite the possibility that it leaves the study open to the charge that it is 'un-Foucauldian' (Graham, 2005, p. 2). In doing so, it is emphasised that the objective was not to conduct a 'perfect' Foucauldian discourse analysis but rather to use whatever tools seemed helpful in providing a better understanding of the influence of academic discourses on privacy discourses in a wider context.

3.1.3 Study design

Since Foucault's conceptualisation of his writing as a tool-box offers the researcher considerable discretion in selecting from the methodologies, it becomes incumbent on the researcher to ensure that the approach selected should be fit for purpose. This analysis was conducted at several levels with the goals of each level shaping the tools selected for the analysis. Given the limited discussion of methods in Foucault's work, the study drew on the secondary literature for guidance in selecting appropriate 'tools'. The study was conducted in three phases. The first involved an analysis of the texts relating to the privacy framework as it operates in Australia. The second phase of the study was the analysis of the health informatics discourses, and the third phase was the analysis of the relationships between the discourses. The study employed different texts or data and used different methods to achieve the particular goals of each phase. The following discussion describes each phase of the research in terms of its purpose, the texts or data used, and the methods adopted to analyse the data.

3.2 Setting parameters: the privacy framework

3.2.1 Purpose

The impetus for the study was the suggestion that the way the Australian privacy framework constructed issues related to personal health information supported systemic function creep (Clarke, 2005; Stalder, 2002a). The study was specifically interested in the way in which the health informatics community supported or challenged the construct and operation of the privacy framework. To explore this, it was first necessary to determine the way the framework constructed issues around the use of personal health information. This provided a context for the later phases of the study. No relevant comprehensive analysis was identified in the literature. Therefore, a preliminary step in this study was to describe the constructs, structures and processes that comprise the privacy framework. In doing so, particular attention was paid to the Commonwealth legislation which underpins other initiatives including state legislation and health policies and protocols. The analysis sought to identify concepts in the privacy framework and to determine how they were interpreted and used. The outcome, discussed in Chapters 4 and 5, was a description of the way the privacy framework was presented, supported, challenged and critiqued.

3.2.2 Texts

Texts used for this phase of the analysis included official documentation emanating from the formal monitoring, administering and evaluation processes of the privacy framework, together with commentaries prepared by stakeholder groups and academic and professional communities. State and federal governments and their departments and instrumentalities, including federal and state privacy commissioners vested with the responsibility for overseeing the framework, produced much of the official documentation. Official information sources were accessed for descriptions of legislation, educational material, reviews, reports, and findings from formal investigations. The information on these sites was prolific and included general introductions, fact sheets and

explanations of the legislation, as well as information sheets specifically directed towards the use of personal health information. Annual reports from Privacy Commissioners were also available, as were findings from formal investigations of complaints. It was expected that these documents would reflect the way the official discourse defined personal information issues and thereby establish parameters within which solutions could be considered. Responses to this official documentation came from a range of groups and organisations including the Australian Privacy Foundation, the Australian Law Reform Commission and various professional and stakeholder organisations. These were the source of commentaries, submissions, public statements and press releases responding to official publications, findings and reviews. Texts relating to significant events, such as the Australian Law Reform Commission review of the privacy legislation, or privacy issues reported in the media, together with conference and journal publications were included in the analysis. The material also included analyses, critiques or opinion papers published in the academic and professional literature. It was expected that these critical discussions would reflect the range of understandings within the parameters established by the discourse, while also pointing to possible alternative, marginalised understandings. The texts spanned two decades, from the early 1990s until the end of the first decade of the twentieth century. This allowed changes over time to be identified. The texts used for this part of the study are included in the general references at the end of the thesis.

3.2.3 Methods

The documents were analysed to identify the way the official discourse defined personal information issues and thereby establish parameters within which solutions could be considered. They were then reviewed to identify strategies used to support, challenge or critique the framework. While this was a systematic and iterative process to identify recurring, shared concepts and theses about privacy and the use of personal information, the process was a

critical review of the literature rather than a Foucauldian influenced discourse analysis.

3.3 Health informatics discourse analysis

3.3.1 Purpose

This second phase, and the main focus of the study, identified health informatics discourses. A brief summary of the historical narrative of the academic discipline provides a starting point for the analysis. This narrative was developed by referring to relevant documentation within the health informatics literature. The historical analysis represents the accepted view of the development of the discipline. The discourse analysis challenges the historical representation of health informatics. It does so by writing a ‘history of the present’ (Roth, 1981, p. 43).

3.3.1.1 History of the present

Rather than being a traditional historical narrative that focuses on describing the progressive knowledge development of the discipline, a history of the present searches for discontinuities and contradictions. Foucault’s comments on the growth of medical knowledge offer some insight into this approach. ‘A historical analysis of medical knowledge has demonstrated that, over short periods of time, medicine not only changed what was accepted as true or false propositions, but also changed the ways of practicing, and interpreting evidence to support practice’ (Foucault, 1980, p. 112, cited in Gastaldo & Holmes, 1999, p. 234). Foucault argued that these changes were not the result of advances in medical knowledge, but were influenced by ‘political, social and historical factors, by power, in human societies’ (O’Farrell, 2005, p. 54). Foucault therefore argued that disciplinary knowledge was not a process of objective accumulating facts but was instead a struggle whereby competing discourses seek to assert truth claims over others. Identifying this struggle involves identifying the discontinuities and ruptures that signal a change in the relative

influence of discourses: 'Collecting historical fragments will allow shifts in the delineation and alignment of discourses to be mapped over time' (McHoul & Grace, 1993, p. 21). While much narrower in focus than Foucault's broad historical analyses, this study sought to produce a history of the present for the academic discipline of health informatics. It was based on his archaeological and genealogical methods.

3.3.1.2 Giving order to history

Kendall and Wickham suggest that 'archaeology and genealogy and discourse are the tools Foucault uses to give some order to history at the same time as giving history the power-knowledge twist that makes the Foucauldian approach so distinctive' (Kendall & Wickham, 1999, p. 22). Some Foucauldian analysts approach archaeology and genealogy as quite separate strategies while others see them as intertwined (Dean, 1994; O'Farrell, 2005). Foucault himself expressed the latter view: 'I never stopped doing archaeology. I never stopped doing genealogy. Genealogy defines the target and the finality of the work and archaeology indicates the field with which I deal in order to make a genealogy' (cited in Mahon, 1993, p.140). Perhaps the important point to make when undertaking a Foucauldian analysis is that the approach is not concerned with the particular corpus of knowledge that is generally accepted to comprise a discipline, but focusses on the sub-strata beneath disciplinary knowledge where the rules and conditions that allow this particular version of knowledge to dominate are at play. As O'Farrell explains:

Archaeology addresses a level at which differences and similarities are determined, where things are organised to produce manageable forms of knowledge while genealogy deals with precisely the same substrata of knowledge and culture, but it is about the 'constraints that limit the orders of knowledge (2007).

In his earlier work, Foucault spoke of archaeology as the means for challenging the representation of history as a coherent, integrated body of knowledge. With

archaeology ‘one is trying to detect the incidence of interruptions that suspend the continuous accumulation of knowledge’ (Foucault, 1972, p. 4). This involves identifying and exploring the internal structure of a discourse. Genealogy is less concerned with internal process of discourse development and more focused on the relationship between a discourse and the social environment. Foucault described genealogy as ‘an overview from higher and higher up, which allows the depth to be laid out in front of him [the genealogist] in a more and more profound visibility’ (cited in Dreyfus & Rabinow 1983, p. 107). The purpose of this study was to identify discourses and their relative influence within the discipline of health informatics. This pointed to the adoption of methods that focused on the ‘level at which differences and similarities are determined, where things are organised to produce manageable forms of knowledge’ (O’Farrell, 2007). The following discussion describes the tools and strategies used for this analysis. These were shaped by what Davidson suggests as Foucault’s ‘own, succinct retrospective interpretation of his archaeological method’ (in Hoy, 1986, p. 221). Foucault states that ‘truth is to be understood as a system of ordered procedures for the production regulation, circulation and operation of statements’ (cited by Davidson, in Hoy, 1986 p. 221).

3.3.1.3 The statement

For Foucault, the basic unit of a discourse is the statement. ‘A statement is something that privileges particular ways of seeing and codifying certain practices’ (Graham, 2005). Kendall and Wickham point out that recognising a discourse as a corpus of statements emphasises that for Foucault discourse and language are not synonymous (Kendall & Wickham, 1999, p. 42). A statement may be a sentence, a phrase, an exclamation, a visual symbol, a diagram or an image. The presence of regular and systematic statements points to a discourse (Gutting, 1994; Hall, 1997; Mills, 2003). For this study, statements included conference proceedings, individual papers, editorials, sentences, or phrases, titles of texts, exclamations, visual symbols, diagrams and images.

Statements are located in the archive. Foucault used the term archive not in the generally accepted sense of a passive collection of records from the past, but as ‘an active and controlling system of enunciation’ (Foucault, 1972, p. 29). Gutting explains: ‘an archive is the locus of prior rules and practices forming the conditions of inclusion or exclusion that enable certain practices and prevent others from being accepted as scientific or moral or whatever other social rubric may be in use at a particular epoch’ (1994, p, 29). In other words, the archive creates the conditions that allow certain statements to be formed and transformed into discourses. Foucault therefore argued that ‘one ought to read everything, study everything. In other words one must have at one’s disposal the general archive of a period at a given moment’ (Foucault, 1972, p. 29). Texts for the study were drawn from the archive.

3.3.2 Texts in the archive

Since a Foucauldian discourse analysis is an historical analysis, it must necessarily be a document analysis, as documents may be the only way to access much of the general archive of the past. ‘Documents are the key elements of the analysis. Reconstruction should be based on the descriptive materials available in documents’ (Lemert & Gillan, 1982, p. 135). Foucault’s studies were grand projects in the sense that he focused on historical epochs. The archive for Foucault’s projects comprised a significant collection of documents spanning broad chronological periods. The scope for this study was much more restricted, focusing on a specific knowledge area in a much shorter chronological period and with much narrower parameters for the research. The archive for this study was bounded by:

- **Geographical parameters:** The study was limited to texts from Australian health informatics literature. This is consistent with Foucault’s argument that the formation of a discourse is ‘always determined in the time and space that have defined a given period and

for a given social, economic, geographical, or linguistic area' (Foucault, 1972, p. 115). Unique historical, cultural and political contexts shaped Australian health informatics discourses. These included government and commercial contexts, the academic institutions where research and learning take place, and the institutional arrangements which structure the delivery of health care. While parallels may be drawn with other jurisdictions, the discourses identified within the texts must be understood in the Australian context with issues surrounding their operation directly applicable to that environment.

- **Institutional/institutional parameters:** A Foucauldian-influenced discourse analysis does not study the rules and conventions of mundane talk; rather, it examines 'serious speech acts or institutionalised talk or practices' (Dreyfus & Rabinow, 1983, p. 45). While texts and practices existed in other sites, it was considered that the literature within the discipline of health informatics represented 'the compendium of existing academic discourses' (Foucault, 1972, p. 129). Health informatics was the site where the discontinuities, innovations, contradictions, comparisons and transformations that give rise to various health informatics discourses were contested. It was also the site which conferred the authority to speak. Therefore, the texts produced specifically by health informatics academics and professionals were central to the analysis, while those produced at other sites were peripheral. The HISA conference is the established and primary means of communication, discussion and information dissemination for the health informatics community. Since papers submitted to the conference were peer reviewed, contributors were considered to be institutionally privileged speakers. The conferences also provide opportunities for a more diverse range of views and positions to be expressed than does the more restrictive *electronic Journal of Health Informatics*. The conference proceedings were therefore considered to be the texts most

likely to incorporate the diversity of discourses that might exist within the discipline.

- **Chronological parameters:** A significant body of texts from the field of health informatics only began to emerge in Australia in 1992, just before the first national conference. The texts included in the study cover the period from 1993 until 2011, although the last available conference proceedings were 2009.

While this proscribed archive offered the potential for an analysis of all documents in the archive, it was determined that within this limited time span, the inclusion of all conference texts could well obscure, rather than highlight more subtle indicators of changes in the discourses, their relationships, and the institutional supports implemented by more successful discourses. For example, it was noted in preliminary analyses that a period where academics engaged in annual relocations between institutions distorted the indicators of emerging discourse communities were identified in the final analysis. It was considered that undertaking a diagnostic of particular points in time to collect the 'historical fragments' would allow finer shifts in the delineation and alignment of discourses to be mapped. The analysis therefore focused on three specific, relatively evenly spaced time periods for analysis of conference texts. These were 1993, the year of the first national health informatics conference, the period 1999-2001, and the period 2006-2009. The description of the discourses was across all of three time periods, while a comparative analysis between each period enabled identification of the changing relationships between discourses. Texts for the analysis were drawn from:

- Health Informatics Society of Australia (HISA) national conference proceedings: This was the primary source of documents. The health informatics community in Australia is relatively small. There are few professional organisations and/or official publications. HISA, established in 1992, was the first health informatics organisation in

Australia. Today it is one of two peak bodies, the other being the Australasian College of Health Informatics (ACHI). HISA has hosted the national conference every year since the inaugural conference of 1993 and this is a primary means of communication, discussion and information dissemination for the field. The conference attracts a wide range of health, computer science and health informatics professionals, together with industry and government representatives. It was viewed as a forum where discontinuities, innovations, contradictions, comparisons and transformations would appear. Papers from overseas contributors were excluded from the analysis. Conference papers are listed in Appendix 1.

- The study included one edition of the *electronic Journal of Health Informatics*. This journal, established in 2008, is the only health informatics journal published in Australia. It is a refereed journal with limited editions each year. One edition in 2008 focused specifically on privacy and security. This provided an additional text for the study. Since contributions to both the conference and the journal are subject to peer review, authors were viewed as institutionally privileged speakers. The journal articles are listed in Appendix 1.

The analysis of the special edition of *electronic Journal of Health Informatics* occurred after the discourses were identified in the conference texts. It was specifically concerned with refining and affirming the way the each discourse constructed issues relating to the use of personal health information.

3.3.3 Methods for identifying discourses

Discourses comprise statements supporting common themes deploying objects, concepts, and subject positions to which determine what can and cannot be discussed. However, while the basic unit of a discourse is the statement, the focus of analysis is not the statement per se. For Foucault, a statement is not an

expression in itself but ‘a function that enables groups of signs to exist, and enables rules or forms to become manifest’ (Foucault, 1972, p. 29). The analysis focussed on identifying objects, subject positions, concepts and strategies that were made visible by the statements. It also explored the context-dependent circumstances in which these elements appeared, recurred, combined and interacted. ‘We must grasp the statement in the exact specificity of its occurrence; determine its conditions of existence, fix at least its limits, establish its correlations with other statements that may be connected with it, and show what other forms of statement it excludes’ (Foucault, 1972, p. 30). While this entailed careful, detailed and iterative practice, Fairclough’s advice that ‘discourse analysts should not follow a pre-set coding list, but be sufficiently sensitive to the presences and absences within a text and to weighing the presences against possible alternatives’ was adopted (Fairclough, 1995, p. 18). Foucault hints at this approach in *Archaeology of Knowledge*, where, in response to his own sequential description for identifying the object of knowledge, he comments that this enumeration ‘has located, one after another, several planes of differentiation in which the objects of discourse may appear. But how can one speak of a ‘system of formation’ if one knows only a series of different, heterogeneous determinations, lacking attributable links and relations?’ (1972, p. 47). To achieve this type of analysis, the secondary literature advocates an iterative reading and re-reading of the texts (Ifverson, 2003; McHoul & Grace, 1983; Potter & Wetherell, 1987). This was the foundation method adopted for this study.

Since the structuring of the object of knowledge establishes the parameters within which the remaining rules operate, the first phase of the analysis focused on identifying different constructs for the object of knowledge (Hall, 1997; Kendall & Wickham, 1999; Mills, 2003). However, while identifying the elements of the discourses is described as a sequential process, it was not so neatly structured. The elements were identified simultaneously and

progressively as reading followed reading. Thus, while the focus in the initial readings was on delineating the objects of knowledge, other elements were noted, refined and developed as the reading progressed. With each reading, the various elements of discourses and their relationship to each other became clearer. In other words, successive iterations built upon, and added to, existing insights. In this way, the discourses emerged from the texts rather than being imposed on the texts by the preconceived expectations of the researcher.

3.3.3.1 Objects of knowledge

Statements within a discourse construct the object of knowledge through use of particular words, phrases, terms of reference, metaphors, rhetorical styles and systematisations of knowledge that construct a particular kind of object, a particular way of speaking about the object and particular subjects who have the authority speak about the object (Foucault, 1972). The delineation of the object of knowledge governs the way the remaining rules operate to construct concepts and conceptual architectures, establish who has authority to speak, and give rise to strategies and themes. Therefore, the initial reading of the texts focused on identifying different constructs for the object of knowledge (Hall, 1997; Kendall & Wickham, 1999; Mills, 2003).

The object of knowledge, as determined by the study questions, was *information*. The analysis therefore sought to delineate the way in which the health informatics discourses constructed and delimited the object *information* in the texts. This required identification of all the terms used to refer to information. The historical narrative incorporated many such terms, including *data, information and knowledge, personal information, de-identified data, aggregated data, information management*. This analysis initially identified these terms but additional recurring terms were added as they were identified. Since the context in which terms are used is integral to identifying and

delineating discourses, they were initially highlighted within the texts rather than being recorded in some form external to the documents.

3.3.3.2 Concepts and conceptual architectures

While discourses within a particular field may share common concepts, each discourse has its own conceptual architecture that links concepts to produce different emphases and priorities. Foucault emphasises that the relationships between concepts are the key to delineating discourses: ‘what properly belongs to a discursive formation and what makes it possible to delimit the group of concepts that are specific to it, is the way in which these different elements are related to one another’ (1972, p. 60). Thus, a conceptual architecture that uses specialised jargon such as *archteypes*, *predicate calculus*, and *conceptual schema languages* establishes technology and technical issues as being within the discursive formation. Linking concepts such as *balanced scorecard*, *strategic methodology* with *improved market position*, *financial results*, and *customer satisfaction* establishes a very different understanding of what is appropriate for the discourse to address. Concepts such as *information technology*, *privacy*, or *security* might be common across a number of discourses, but may be ordered and linked differently, attributing one a central role while subordinating others. Concepts were initially identified and marked in-text. This facilitated a comprehensive understanding of the way terms were used, the frequency and regularity of their appearance, the way they were linked, and the contexts in which they were used. As the reading of the texts progressed, statements with similar linkages, groupings or progressions of concepts became visible. These were grouped and listed as pointing to possible discourses. Table 3.1 lists examples of conceptual architectures found in the texts.

Table 3.1: Examples of conceptual architectures

Archetypes (Clinical knowledge) = data instance = Display technology = custom views = usefulness, user acceptance, usability
Clinical data, clinical meaning = Modelling = rules = software (Attributes)
CPOE systems = eliminate handwritten orders and charts = reduce errors = improvements in quality and efficiency of health care delivery = patient outcomes = efficiency gains
Duty of care = Information delivery system (as adjunct to doctor-patient relationship) = improved information + education = increased comprehension = Informed consent
Patient journey modelling = efficiency = improved quality care
BSC strategic methodology = improved market position, financial results, customer satisfaction
Statutory requirements = Clinically relevant data = monitoring and benchmarking = more appropriate, effective care
Technology = user interface = efficient alternative to paper = effective Clinical audits
Adequate security = privacy
Algorithm = mapping terms into concepts = interoperability of systems
CDSS = facilitate evidence based clinical practice = substantially improve health care quality
Modelling: user analysis + environmental analysis = web site design;

3.3.3.3 Subject positions enunciative modalities

Foucault argued that a particular discourse produces a number of subject positions that are related to one another in a status hierarchy that determines who has the authority to speak and who does not. Enunciative modalities determine what role the subject assumes within a specific discursive and institutional field (1972, p. 55). Therefore, subject positions were identified by exploring the formation of enunciative modalities. To achieve this, the analysis asked:

- *Who is speaking?* In answering this question, the focus was not on individual authors, but their status as clinicians, managers, researchers or academics. Information enabling identification of speaker status was not always available, particularly in the earlier texts.

- *What institutional and technical sites did statements originate from?* Sites included academic faculties and schools, divisions and departments within health organisations, and commercial sites
- *What is the relationship between the various subject positions identified in the discourse?* This enabled identification of status hierarchies. Subject positions give the experts the power to research, to teach, to write and to speak as experts. In Foucault's words, 'who, among the totality of speaking individuals, is accorded the right to use this sort of language? Who is qualified to do so? Who derives from it his own special quality, his prestige, and from whom, in return, does he receive if not the assurance, at least the presumption that what he says was true?' (Foucault 1972, p. 50). The historical narrative pointed to many statuses within the discursive field, including *clinician*, *nurse*, *patient*, *manager*, *client*, *IT professional* and *user*. However, the analysis found variations in these subject positions and the way they were ranked. Different status hierarchies were linked to particular understandings about information and information use. Thus, a status hierarchy which privileged nurses was linked with a privileging of nursing knowledge and practice.

As with identifying objects, concepts and conceptual architectures, status positions were identified and marked in-text during the re-iterative reading of the documents. In the initial readings all statuses were noted as they occurred. Later iterations noted linkages between concepts, such as *clinician* and *client*, *IT technician* and *user*, or *health professional* and *consumer*. The analysis also noted the absence of some statuses in some contexts. For example, did *consumer* and *patient* appear in the same discussion? Changes across the three sets of texts were identified. The regularity of linkages and absences pointed to the presence of status hierarchies.

3.3.3.4 *Themes*

Themes establish the parameters for appropriate and acceptable activity within a discourse by applying rules of inclusion and exclusion. These rules promote a particular view within the discourse by allowing some statements while prohibiting others. For example, in a biomedical discourse, scientific statements may be legitimised while other forms of knowledge are excluded. Foucault refers to themes and theories as strategies since they establish parameters for appropriate and acceptable activity within a discourse. They apply the rules of inclusion and exclusion to structure the deployment of objects, concepts, and subject positions and determine the object of knowledge, the proper form that concepts and theories must assume when speaking of the object of knowledge, and who has the authority to speak about the object of knowledge (Foucault, 1972).

Identifying themes involved looking for statements that consistently linked key terms to create a specific understanding of the issues. Examples included statements that regularly linked discussions around security and privacy in such a way that security appears as the obvious and logical solution to managing privacy, or statements that represented increasingly intrusive management practices as reasonable and much needed responses to the problems of health care. The analysis also identified the way linguistic strategies were used to validate and reinforce the legitimated view. Linguistic strategies included use of metaphors and rhetoric, binary oppositions and truth claims to justify a particular view or disarm opposition. Metaphors and rhetoric included use of the terms such as *battle* or *weapon* to construct a particular perception of relationships between professional groups. Truth-claims were used to justify a particular position, for example, a crisis in health care, were used to justify increased monitoring of the activities of health professionals. Binary oppositions were used to disarm opposition by contrasting ‘new’, ‘modern’ systems with ‘old-fashioned’ ways, or comparing electronic data analysis as

‘reliable’, ‘valid’ and ‘providing a solid basis for planning and policy making’ with less positive references to ‘subjective’ decision making. Questions to identify themes included:

- What is being represented as a truth or a norm?
- How is this constructed? What is included and what is excluded?
- What is made problematic and what is not?
- What alternative meanings/explanations are ignored?

Through the iterative reading and re-reading of the texts, similar statements, suggesting possible themes were grouped and recorded externally to the texts. In this way, the pattern of the discourses began to emerge. At this point, the texts were deconstructed and recurring objects, conceptual architectures, status hierarchies and themes associated with a particular discourse were grouped together. In this way, discourses were differentiated. The discourses identified by this process are described in Chapter 6. Once discourses were delineated, the analysis moved on to identify and describe the relationships between the discourses.

3.4 Relationships between discourses

3.4.1 Purpose

The purpose of this stage of the analysis was to determine the relative influence of individual discourses and the changes in this influence over time. A successful discourse is the talk of specific academics and professionals, issued from specific institutional sites by authorised speakers and distributed through specific institutional channels. This institutional presence is the outcome of political struggles that result in networks of institutional processes and relations that control the production, dissemination and application of disciplinary knowledge. ‘Discursive struggles may also be reflected in the minutiae of changing institutional structures and practices’ (Sharp & Richardson, 2001, p. 15). The analysis sought to identify these institutional processes, practices and

social relations that more dominant health informatics discourses were able to impose as they sought to shape and control the emerging academic discipline of health informatics.

3.4.2 Texts/data

For this phase of the analysis, conference texts, were supplemented with official publications from HISA and ACHI. These two organisations claim to be the peak organisations for the health informatics community, to represent the views of the community and to speak on their behalf. It was considered that the official texts produced by these bodies would reflect the dominant discourses within the community. The analysis also explored official documentation from government, academic and research institutions, professional organisations, journals and other publications. These texts are therefore listed within the general references that informed the study.

3.4.3 Methods

The analysis therefore focused on the time periods during which conference texts were analysed. These were 1993, the year of the first national health informatics conference, the period 1999-2001, and the period 2006-2009. The comparative analysis between each period enabled identification of the changing relationships between discourses. This comparative analysis also pointed to emerging institutional processes and relations.

As with many aspects of Foucauldian influenced analyses, there was no clear indication, either in his work, or in the secondary literature, about which institutional processes and relations are considered significant. This study, based on both Foucault's work and discussion in the secondary literature, used the following to as indicators of discourses establishing institutional support:

- Institutionalised processes supporting the production and dissemination of disciplinary knowledge and practice: the analysis looked for the presence of specifically designated health informatics faculties,

departments and schools with teaching and research programs focused on the production, dissemination or application of health informatics knowledge.

- Mechanisms to control the production of health informatics skills and knowledge: These mechanisms transcend the activities of individual institutions, operating as disciplinary-wide bodies that seek to control understanding about what constitutes valid knowledge in the subject area and what constitutes a valid approach to seeking and using that knowledge. They include processes that established academic standards, defined curricula and skill sets and implemented professional accreditation procedures.
- Mechanisms to accredit an identifiable system of status positions acknowledging health informatics expertise: Authorisation to speak is conferred via qualifications, profession, and status position in the network of power/knowledge. Such positions are related to one another in an hierarchy of authority and control. The analysis looked for evidence of academic qualifications and professional accreditation, and a status hierarchy which conferred the authority to speak.
- Organisations that promote the discipline and profession: These organisations transcend individual institutions to implement discipline/profession wide governance processes. Through the establishment of membership criteria they create a community of academics and professionals who share particular characteristics and ideas about who they are, what they do, and how they do it. On the basis of membership, these organisations appropriate the authority to speak on issues pertinent to the discipline and the profession. The analysis sought evidence of such organisations.

- Mechanisms for dissemination of approved knowledge: these included the organisation of conferences and the creation and publication of journals. Control of these mechanisms reinforced approved knowledge, practices and social relations of the discipline.
- An identifiable active community of interest: social processes and social relations produce communities of scholars and professionals who have a shared understanding of what constitutes valid knowledge and what represents a valid approach to seeking that knowledge. The analysis looked for indications that authors, academics and professionals experienced a sense of belonging to a health informatics community.

For each of the three conference periods, institutional processes and relations were identified and the relative power of the discourses in generating these social practices was explored. This re-emphasised that the development of health informatics was not an evolutionary, cumulative process but was local, ad hoc and piecemeal, linked to the distribution of power and power relationships within the discipline. The relationships between discourses identified in this study are discussed in Chapter 7.

3.5 Limitations of the research design and methodology

The limitations of discourse analysis largely arise from the methodology on which it is based (Cheek, 2000; Powers, 2001). ‘Since no claim is made for the absolute truth of the claims made in a discourse analysis, one of the limitations is that other, competing claims are possible regarding the same discourse’ (Powers, 2001, p. 63). Consequently, this study cannot claim to be the definitive analysis of discourses present within the academic discipline of health informatics. Others, using the same theoretical framework and methodology, might find more, fewer or different discourses. Discourse analysis will always remain a matter of interpretation and this study will represent one interpretation of health informatics discourses. In addition, the

results of a discourse analysis are not generalisable to other situations, other discourses or other people, since they are a matter of the social, historical and political conditions under which statements come to count as true or false (McHoul & Grace, 1993). At the same time, the study may be useful in generating discussion amongst those working in the field of health informatics.

Selection of texts may also be a limitation of the study. Foucault himself was criticised for being ‘highly selective in his use of sources, quoting only from those that supported his broad observations’ (Sharp & Richardson, 2001). This criticism could be directed at any discourse analysis, given the range of texts potentially available. The focus on officially sanctioned documentation in this study might suggest an assumption that discourses in the official documents carry more weight and influence than discourses in other sites. However, as noted in the earlier discussion, the literature within the discipline that represents the site where the discontinuities, innovations, contradictions, comparisons and transformations which give rise to various health informatics discourses will be contested and is therefore of primary interest to the study.

Mechanisms to ensure trustworthiness, confirmability and auditability are intended to address these limitations. These mechanisms include a clear description of the processes for identifying, collecting and analysing data. This chapter has sought to establish these mechanisms by providing the rationale for selecting texts and other data sources, and by clearly explaining the approach used to analyse data. As an additional mechanism, statements used to illustrate aspects of the discourses are attributed to the author who made them and these are listed in the appendices at the end of the thesis. In doing so, Foucault’s view that ‘subjects are not the initiators of discourse, but are simultaneously the products of discourse and a means by which discourses are propagated’ (James, 2004, p. 17), is acknowledged. This means that the intent of individual authors is not part of the analysis, since the discourses determined who the health

informatics experts were and what they could say. Where statements have been attributed to specific authors, this is for purposes of trustworthiness confirmability and auditability, rather than to individualise and attribute statements to particular authors.

These perceived limitations need not detract from the overall value of the study. The goal of the discourse analyst is to draw attention to the relationships between power and knowledge. In doing so, the study adopts the position that 'the process of analysis is always interpretive, always contingent, always a version or a reading from some theoretical, epistemological or ethical standpoint' (Wetherall, 2001, p. 384). There will always be other perspectives from which to interpret the material under review

Chapter 4: The privacy framework

4.1 Introduction

The context for the study was the suggestion that the construction of issues around the use of personal information in the Australian privacy framework supported systemic function creep (Clarke, 2005; Stalder, 2002a). The analysis therefore began with a critical review of legislation and associated documents related to Australia's privacy framework. This chapter describes the outcomes of this review, outlining the constructs, structures and processes that comprise the privacy framework. In doing so, particular attention is paid to the Commonwealth legislation which underpins other initiatives including state legislation and health policies and protocols. The chapter begins with a discussion of the way the concept 'privacy' is understood and used in the legislation. This understanding shapes the issues and solutions considered to be within the parameters of the framework. This is followed by a brief summary of the specific federal and state legislation. The concepts that underpin the operation of the framework are then considered. The analysis points to the power of some groups to shape the privacy framework.

Analysis of the privacy framework was based on texts from official documentation emanating from the formal monitoring, administering and evaluation processes of the privacy framework. State and federal governments and their departments and instrumentalities, including federal and state privacy commissioners vested with the responsibility for overseeing the framework, produced much of the official documentation. Official information sources were analysed for descriptions of legislation, educational material, reviews, reports, and findings from formal investigations. The documents were analysed to identify the way the official discourse defined personal information issues and thereby establish parameters within which solutions could be considered. While

this was a systematic and iterative process to identify recurring, shared concepts and statements about privacy and the use of personal information, the process was a critical review of the literature rather than a Foucauldian influenced discourse analysis.

4.2 Defining privacy

The difficulty in defining privacy is illustrated by the fact that in the Commonwealth privacy act, we have an act dedicated to privacy, yet it does not define it (Crompton, 2001).

In Australia, the management of personal health information is constructed as an issue of individual privacy. This is clearly indicated in the naming of the key federal legislation as the *Privacy Act, 1988*. Yet Versey notes that ‘it is hard to define what is being protected when we talk about the right to privacy’ (2007). As the discussion in surveillance literature indicated, privacy is a dynamic, multi-dimensional concept. In practice, it tends to be defined in general, rather than specific terms, and the definition changes in response to changes in political, economic, technical and cultural circumstances (Bennett, 1996; Crompton, 2001; Foord, 2002; Westin). In democratic societies privacy is understood as a fundamental human right, linked to dignity and autonomy and thus protected in social institutions. Yet while highly valued, it is represented as having a Janus face: ‘We seek privacy and often anonymity, but we also know that privacy can hide dastardly deeds’ (Marx, 2007). Disclosure of some personal information is therefore accepted as necessary to enable democracies to function effectively (Byrne & Cooper, 2006; Crompton, 2001; Versey, 2007; Westin, 2003). This argument reflects the rationale of the discussions that utilise a neutral definition of surveillance. It also underpins the Australian privacy framework in which privacy is defined in relative rather than absolute terms: ‘The right to privacy is not absolute. In some circumstances it must be balanced with the rights of others and with issues that benefit society as a whole’ (Office of the Privacy Commissioner, 2010). With regard to health

information, these benefits are expressed in terms of better and more convenient services, improved patient safety, greater efficiency, more effective use of resources and improved population health status and productivity (Australian Health Ministers Advisory Council, 2009).

The understanding of privacy as relative shapes institutional initiatives to manage privacy. This begins with the legislation. The 2005 review of the *Privacy Act 1988* recognised the legitimacy of both individual interests and other competing interests, including business efficiency and the free flow of information (Curtis, 2007). The Victorian *Charter of Human Rights and Responsibilities* (2006) grants the right of a person ‘not to have his or her privacy, family, home or correspondence unlawfully or arbitrarily interfered with’ (Versey, 2007). These statements allow that there will be situations where ‘interference is justified’ (Federal Privacy Commissioner, 2002; Versey, 2007). Situations where interference is considered justified include:

- Where the privacy of an individual or group may conflict with some other interest and may have to be traded off: to gain access to health care, an individual will need to divulge a certain amount of personal, even sensitive information.
- Where the privacy of an individual or group may conflict with the interests of other persons or groups: for example, in the situation where the test results for a patient reveal information that potentially impacts on other family members: ‘Do others in the direct genetic line have the rights to know that information?’ (Crompton, 2001, p. 11).
- Where the privacy of an individual or group may conflict with the interests of the wider community: for example, where there is a need to protect the public against a serious disease.

Research suggests that the Australian community generally accepts this construction of privacy as relative, acknowledges the existence of other rights and responsibilities, and accepts the legitimacy of the argument that there is a need to strike a balance between them. The Australian Law Reform Commission (ALRC) observes that ‘people appreciate that other interests often come into the balance – such as freedom of speech, child protection, law enforcement and national security’ (Australian Law Reform Commission, 2008a). The preliminary report of the International Survey on Privacy and Surveillance also found that ‘the majority of citizens in all countries (in the survey) are accepting of having their personal information shared with government agencies’ (Chan et al., 2008, p. 27). This demonstrates the acceptance of the privacy/public interest balance as an appropriate approach to defining issues related to the use of personal information. The survey also found that ‘prior consent and the suspicion of wrong doing are regarded in all countries as important factors when it comes to sharing personal information’ (Chan et. al., 2008, p. 27). While this points to community expectation re controlling the use of information, it does allow an opportunity for function creep in the face of strong public interest arguments. The privacy framework, underpinned by federal and state legislation, is considered an appropriate mechanism for negotiating an acceptable balance between the individual’s right to privacy and other interests.

4.3 Federal and state legislation

Privacy law in Australia comprises several Commonwealth (federal) statutes covering particular sectors and activities, some state or territory laws and the residual common law protections. The primary Commonwealth statute dealing with personal information is the *Privacy Act, 1988 (Cwlth)*. This Act originally applied only to the Commonwealth public sector but was amended in 2001 to extend its reach to some private sector organisations and businesses, including all private sector organisations that hold health information and provide health

services. ‘A health service includes any activity that involves assessing, recording, maintaining or improving a person's health; diagnosing or treating a person's illness or disability; or dispensing a prescription drug or medicinal preparation’ (Office of the Federal Privacy Commissioner, 2001). Private sector services covered by the Commonwealth legislation include traditional health service providers such as private hospitals and day surgeries, medical practitioners, pharmacists, and allied health professionals, as well as complementary therapists, gyms and weight loss clinics (OFPC, 2001). Federal privacy law does not regulate state or territory agencies. These have approached privacy protection within their own jurisdictions in various ways. Table 4.1 outlines legislation and other privacy protection measures adopted by the Commonwealth, states and territories.

Table 4.1 Commonwealth state and territory privacy measures

Jurisdiction	Privacy Safeguards	Regulator
Commonwealth	<i>Privacy Act 1988 (Cwlth)</i> Amended in 2002 to cover some private sector organisations, including all organisations delivering a health service Overseen by the Federal Privacy Commissioner	Australian Privacy Commissioner
Queensland	<i>Information Privacy Act, 2009 (Q'land)</i>	Queensland Information Commissioner
New South Wales	<i>Privacy and Personal Information Protection Act 1998 (NSW)</i> , applies to state and local government agencies	NSW Privacy Commissioner
Victoria	<i>Information Privacy Act 2000 (Vic)</i> , applies to state and local government agencies <i>Charter of Human Rights and Responsibilities Act 2006</i> establishes a general right to privacy for individuals,	Victorian Privacy Commissioner Victorian Equal Opportunity and Human Rights Commission
Tasmania	<i>Personal Information Protection Act 2004, (Tas)</i> applies to state public sector bodies and local councils	Tasmanian Ombudsman
South Australia	Cabinet Administrative Instruction 1/89	Privacy Committee of South Australia
Western Australia	No current privacy regime; <i>Information Privacy Bill, 2007</i> was introduced into Parliament in March 2007 but lapsed	

	when Parliament was dissolved for the 2008 State election.	
Australian Capital Territory	<i>Privacy Act, 1988 (Cwlth)</i> <i>Human Rights Act 2004</i> establishes the right to privacy for individuals	Australian Privacy Commissioner Human Rights Commission
Northern Territory	<i>Information Act 2002</i> covers the protection of personal information, record keeping and archive management of information held in the public sector.	Northern Territory Information Commissioner

Health information is perceived as particularly sensitive in a number of jurisdictions. Commonwealth legislation has a separate section dealing with health information and most states have introduced health specific information legislation. As with privacy legislation generally, the states and territories have ‘a patchwork of enactments mandating confidentiality and privacy of health information. In some jurisdictions there are dual regimes governing the handling of health records while in others there is incomplete coverage, due to a lack of public sector privacy laws in some states’ (Longstaff, 2005). These different approaches are summarised in Table 4.2.

Table 4.2: Health specific privacy measures

Jurisdiction	Health	Regulator
Commonwealth	Separate section of the <i>Commonwealth Privacy Act, 1988</i> . This applies to Australian and Act government agencies Amended in 2002 to include all private sector organisations that deliver health services, including all small health services that hold health information	Australian Privacy Commissioner has been assigned special responsibilities with regard to health information.
Queensland	Specifically addressed in the <i>Information Privacy Act, 2009</i> Information Standards 42A (Health) <i>The Queensland Health Quality and Complaints Commission</i> : provides a health complaint system including privacy-related complaints involving the State public health sector. Private sector service providers subject to <i>Privacy Act 1988 (Cwlth)</i>	Health Quality and Complaints Commission
New South Wales	<i>Health Records and Information Privacy Act 2002 (NSW)</i> , applies to state and local government, private sector persons and organisations	Public Sector: internal review Private sector: Privacy NSW

	Private sector service providers are also subject to <i>Privacy Act 1988 (Cwlth)</i>	
Victoria	<i>Health Records Act 2001 (Vic)</i> , applies to all identifying personal information collected by health service providers in Victoria Private sector service providers subject to <i>Privacy Act 1988 (Cth)</i>	Victorian Health Services Commissioner
Tasmania	Use of health information falls within the <i>Personal Information Act, 2004 (Tas)</i> Private sector service providers subject to <i>Privacy Act 1988 (Cth)</i>	Australian Privacy Commissioner
South Australia	Code of Fair information Practice applies to South Australian Department of Health; Private sector service providers subject to <i>Privacy Act 1988 (Cth)</i>	Australian Privacy Commissioner
Western Australia	No current regime for state services Private sector service providers subject to <i>Privacy Act 1988 (Cth)</i>	
Australian Capital Territory	<i>Health Records (Privacy and Access) Act, 1997</i> (amended) commenced in 2006; applies to health service providers in the public and private sector	Community and Health Services Complaints Commissioner
Northern Territory	No separate regime; falls within the <i>Information Act 2002</i> Private sector service providers subject to <i>Privacy Act 1988 (Cth)</i>	Australian Privacy Commissioner

These laws interact with other federal and state legislation to create a complex network with the espoused purpose of supporting privacy and related rights. *The Equal Opportunity Act, 1995 (Vic)*, for example, makes it unlawful to ask people for sensitive personal information, while the *Northern Territory Information Act, 2003* incorporates issues relating to privacy, freedom of information (FOI), and records management in one piece of legislation. A similar approach at a national level was flagged by Senator John Faulkner in 2008: ‘The Rudd Labor Government will take a comprehensive approach, encompassing both the citizen’s right to know (FOI) and the citizen’s right to privacy’ (Office of the Privacy Commissioner, 2008). In November 2010, the Office of the Privacy Commissioner (OPC) was integrated into the Office of the Australian Information Commissioner (OAIC). This highlights the construction of privacy as linked to autonomy and control: ‘It is the individual’s right to control the use and circulation of their personal

information, and the need to avoid harm to the individual through use or disclosure' (Magnussen, 2004, p. 688).

At the same time a number of federal and state acts incorporate provisions that override privacy laws. These provisions can require organisations to release confidential information they may hold. Taxation, social security and criminal law enforcement legislation contain provisions of this kind:

The Privacy Act does not override specific legal obligations relating to use or disclosure of personal information. 'Law' includes Commonwealth, State and Territory legislation, as well as common law (Office of the Privacy Commissioner, 2009).

Such provisions underline the conceptualisation of privacy as relative. They implicitly acknowledge that privacy considerations can and will be overridden. In one example, Versey (2007) points to the Commonwealth Department of Human Services, which frequently seeks access to state databases by invoking its powers under the *Social Security (Administration) Act*. Legislation may also be modified to change the conditions of its operation. The Australian government, when advised that its intention to use Medicare numbers for the 2003 pilot of the MediConnect electronic prescription record represented a breach of the *Privacy Act*, advised that 'it would legislate its use in MediConnect thus overriding the limitations of the Privacy Act' (AMA, 2006, p. 1). In 2006, the NSW Government 'granted itself an exemption' from privacy legislation for its Healthelink electronic health records pilot project (Fernando, 2009b).

The juxtaposition of Commonwealth and state responsibilities, which creates regulatory overlap of some private sector services and gaps in the coverage of some public health services, together with the exceptions and exemptions, has resulted in a complex and cumbersome framework. While generally viewed as a positive attempt to protect the personal information of citizens from

unauthorised use or disclosure (Clarke, 2005; Skene, 2008), the framework has been consistently criticised both for this complexity and for lack of clarity (Clarke, 2005; Skene, 2008):

The heavily amended Act now comprises 253 pages of the most tortuous legalese imaginable...they have all manner of exceptions and exemptions scattered through them, and the undefined term 'reasonable' appears 24 times (Australian Privacy Foundation, 2010).

These criticisms were acknowledged in the Australian Law Reform Commission's *Review of Australian Privacy Law* (2008) which identified 'a pressing need for simplification and harmonisation of law and practice' (Australian Law Reform Commission, 2008). The three-volume 2700-page review recommended 295 changes to privacy law, including the need to draft new privacy guidelines to regulate the use of health information:

There is significant uncertainty in the community about how the (Commonwealth) Privacy Act and other health laws interact, particularly given the increase in the co-location of public and private service provision (Solomon, 2008, p. 2).

This complexity is considered to be a consequence of the *light touch* legislation that Australia has implemented to manage the multifaceted and increasingly diverse information management issues.

4.3.1 Light touch legislation

Light touch legislation is not prescriptive, but adopts a co-operative, partnership approach encouraging stakeholders to participate in the development of privacy protection regimes that will suit the diverse situations to which they apply. In the Commonwealth privacy legislation, a light-touch approach has been achieved by avoiding a definition of privacy and structuring the framework around Information Privacy Principles (IPPs) and National Privacy Principles (NPPs). The former apply to Commonwealth and ACT government agencies, while the latter apply to those parts of the private

sector which fall within the parameters of the federal legislation. State legislation is modelled on the Federal statute. With regard to health information, the Office of the Federal Privacy Commissioner (2002) notes that the principles address:

- The storage, use, disclosure and retention of individual claims information under the Pharmaceutical Benefits Scheme and the Medicare program;
- Privacy standards in the conduct of human medical research in Australia;
- The collection, use and disclosure of personal medical information in relation to the conduct of research, compilation and analysis of statistics relevant to public health, safety or health service management activities; and
- The collection, storage, use and security of personal tax file numbers by organisations that are authorised or approved to record such information under taxation, assistance agency or superannuation law

The Principles offer broad guidelines which provide the basis for organisations to develop *best practice* policies and protocols specific to their environment and circumstances: ‘It is substantially reliant on self-regulation and as a consequence much depends on the development of codes of practice’ (Caslon Analytics, 2008). The principles apply only to information the legislation defines as personal.

4.3.2 Defining personal information

Federal legislation differentiates between personal information (which includes sensitive and health information), which is within its sphere of influence, and de-identified information which does not fall within the

parameters of the privacy framework. While specific definitions may vary within state legislation, the following definitions generally apply:

- Personal information means information or an opinion (including information or an opinion forming part of a database), whether true or not, and whether recorded in a material form or not, about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion.
- Sensitive information is a subset of personal information, and is information about matters like racial or ethnic origin, political opinions, membership of certain organisations, and health. Tighter limits are imposed on handling sensitive (and therefore health) information.
- Health information is a subset of sensitive information and consists of details about a person's health status, disability, use of health services, and other personal information collected during a health care encounter.

The definition of personal has 'a quality of *intrinsic identifiability*, meaning that what can be used to identify a person must be contained in the information itself' (Thomson, 2005, p. 315). Information that lacks this characteristic is considered to be de-identified. It is assumed that such information cannot be used to identify individuals and therefore on its own is not potentially damaging. The Act both establishes parameters for the use of personal information but also identifies situations where these parameters may be exceeded. Genetic information, for example, falls within the definition of personal health information and its use is subject to the limitations outlined within the legislation. However, the Commonwealth legislation was amended in 2003 to allow for the release of personal genetic information in certain situations (Crompton, 2001; Skene, 2008). The amended *Privacy Act 1988* (*Cwlth*) states that:

- The Commissioner may approve guidelines relating to use and disclosure of genetic information for lessening or preventing a serious threat to the life, health or safety (whether or not the threat is imminent) of a genetic relative.
- An organisation may disclose genetic information if it reasonably believes use or disclosure is necessary to lessen or prevent a serious threat to the life, health or safety (whether or not the threat is imminent) of a genetic relative.

Although generally considered as a subset of personal/sensitive information, not all health information is automatically included. Information that contains details of a person's health condition but is identified by a code number, for example, 'is not personal information if there is nothing in the information itself by which the identity of that person can be reasonably ascertained' (Thomson, 2005, p. 315). It is therefore considered to be de-identified and not governed by the Privacy Act. In the 2005 CAMM Pacific case, the information obtained by the company was stripped of identifying features such as names, addresses and Medicare numbers, leaving data such as postcodes, gender, test results and prescribed drugs. The Privacy Commissioner exonerated the parties involved of any breach of the Act, observing that 'the Privacy Act applies to information where the identity of the individual is apparent, or can reasonably be ascertained, from the information. I found that the data is de-identified and therefore does not fall within the definition of personal information outlined in the Privacy Act' (Curtis, 2005).

The privacy framework relies on the concept of informed consent as an important mechanism for managing ambiguities and confusion around the use of personal information, including the delineation between personal and de-identified data.

4.3.3 Informed Consent

Privacy and data protection acts have tried to solve the contextual and dynamic nature of privacy by building in control by individuals over their personal information through mechanism of choice and consent (Crompton, 2001).

The privacy framework stipulates that consent for use of health information requires that the individual ‘voluntarily agrees to the collection of information after being informed about what information will be collected, how it will be used and who will have access to it’ (Office of the Federal Privacy Commissioner, 2001). The Commonwealth legislation refers to *express* and *implied* consent:

Express consent – consent that is clearly and unmistakably stated and can be obtained either in writing or in any other form where consent is clearly communicated... Implied consent arises where consent may reasonably be inferred in the circumstances from the conduct of the individual and health service provider (Australian Law Reform Commission, 2012).

The legislation outlines situations where consent is required as well as situations where consent may be overridden. Generally, consumer consent is required whenever personal health information is collected, used or disclosed, except in emergencies, for law enforcement or when authorised by law. Situations where consent is required include:

- Health professionals requesting access to a consumer’s record
- Health practitioners sharing health information with other health practitioners
- Bringing together public health information (for example births or cancer registry information) with information gathered from individual health encounters

- Health administrators, researchers, statisticians and policy advisers ‘mining’ health data

As with other aspects of the privacy framework, consent is not absolute. The legislation is qualified by a number of exceptions and exemptions that allow access to personal information on the grounds of public interest. For example, ‘the Victorian legislation allows for research and surveillance activities using identifying data if they are in the public interest or if it is impracticable to seek individual consent’ (Carapetis et al., 2002, p 523). Commonwealth legislation accepts that ‘non-consensual use and disclosure are lawful if for defined purposes and subject to defined conditions, including a privacy review by a human research ethics committee’ (Thomson, 2005, p. 316). Consent requirements may also be modified. This was demonstrated when the NSW state government gazetted a change from an ‘opt-in’ to an ‘opt-out’ model of consent for its electronic health record system, Healthelink. Patients who opted-out would still have their demographic information (name, sex, date of birth, address and home telephone number) kept on the central EHR database.

4.4 Conclusion

Stakeholders seeking access to personal health information must work within the parameters of this legislative framework. At the same time these parameters are regularly challenged as interested parties variously seek increased access to personal information, or increased vigilance in overseeing its use. The framework is constantly evolving, resulting in a complex, dynamic, and contextual mix of legislation, policy and protocols. It is a framework that is widely discussed, analysed and critiqued. Indeed, the official documentation emphasises the importance of stakeholder involvement. This is indicated in the range of responses to the recent Australian Law Reform Commission’s *Privacy Review* (2008) which was described as ‘one of the largest community consultation programs in its history’ (Australian Law Reform Commission, 2008). Consultation processes included face-to-face meetings, workshops, and

roundtables with individuals, organisations and agencies. Public forums, a national phone-in and a website designed specifically to engage young people were also included. In excess of 500 written submissions from a broad cross-section of individuals, private sector organisations and government agencies were received (Australian Law Reform Commission, 2008). This widespread participation is welcomed as evidence of a healthy democratic process.

One of the fascinating aspects of privacy is that there are always new issues to debate and old issues to be revisited. The to and fro of debate is pivotal to a healthy society. When our society is considering the privacy issues arising from the information, we must ensure that it is a rigorous and wide ranging debate in which the whole community takes place (Crompton, 2001)

The discussion, both supportive and critical, emanates from institutional sites and acknowledged experts, including governments, instrumentalities with the authority to oversee the framework, the law, educational and research institutions and consumer and commercial organisations. The next chapter explores this debate, noting both what is discussed and what is excluded.

Chapter 5: The ‘to and fro’ of debate

5.1 Introduction

This chapter summarises the discussion and debate generated by the operation of the framework. The privacy framework, particularly the legislation around which it has developed, has been subject to regular criticism. This criticism primarily focuses on the operation of the framework and its effectiveness in either allowing the access demanded by some, or protecting the privacy expected by others. However some criticisms are directed towards the structure of the privacy framework. These argue that the framework has been shaped to ‘ensure that business was not constrained in its use of data. In other words, to set up a framework to provide the semblance of regulation so that business can get on with its business’ (Clarke, 2005). In doing so, the discussion echoes a number of issues raised in the surveillance literature.

There are several arenas within which discussion and debate occur. These include official documentation discussed in the previous chapter and commentaries prepared by stakeholder groups and academic and professional communities. Texts relating to significant events, such as the Australian Law Reform Commission review of the privacy legislation, or privacy issues reported in the media, together with conference and journal publications were included in this phase of the analysis. This material included analyses, critiques or opinion papers, published in the academic and professional literature. It was expected that these critical discussions would reflect both the range of understandings within the parameters established by the framework, while also pointing to possible alternative, marginalised understandings. The texts spanned two decades, allowing for changes over time to be identified. This phase of the study builds upon the analysis of the official documentation, and therefore adopts the same approach, reviewing the literature to identify themes and

strategies used to support or challenge the construct of information use supported by the privacy framework.

5.2 Official literature: Consensus

The official documentation is primarily produced by state and federal governments and instrumentalities vested with responsibility for overseeing the privacy framework. These include the Commonwealth Department of Health and Ageing (DoHA), the Office of the Privacy Commissioner, (integrated into the Office of the Australian Information Commissioner on November 1, 2010), and the National Electronic Health Transition Authority (NEHTA). The official documentation includes guidelines and manuals, policies and codes of conduct, information and fact sheets, determinations and compliance notes and government documentation. The purpose of this literature is to promote, inform, explain and educate the Australian community about the operation of the privacy framework. In doing so, it adopts a positive perspective, using terms such as ‘trust’, ‘collaboration’, ‘partnership’ and ‘working together’ to create a perception of consensus and cooperation. This is a long-standing approach. In 1999 the Federal Privacy Commissioner observed that ‘the government has decided to develop legislation to support and strengthen self-regulatory privacy protection in the private sector’ (Office of the Federal Privacy Commissioner, 1999, p. 1). Almost a decade later the Federal Privacy Commissioner continued to advocate ‘a principle-based approach to regulation that seeks to change behaviour rather than impose prescriptive rules and regulations’ (Curtis, 2007, p. 7), in other words, a light-touch approach.

5.2.1 Light-touch legislation: Flexibility and responsiveness

The literature promotes the light-touch framework of legislation and professional and ethical guidelines as enabling flexibility and responsiveness to changing environments. Depending on the particular circumstances ‘law, corporate rules or a code may be appropriate to ensure privacy protection’

(Curtis, 2007, p. 13). The lack of prescriptive standards is therefore represented as a strength of the legislation:

Maintaining a principles based approach is appropriate because of the flexibility and responsiveness to change it permits in privacy regulation. Avoiding rigid and prescriptive regulation allows organisations to develop their own solutions as to how they can meet their privacy obligations in a way that matches their circumstances (Office of the Federal Privacy Commissioner, 2008)

While it is acknowledged that flexibility may lead to some confusion, it is justified as necessary to cope with the rapidly changing healthcare environment and increasing technological capability:

An effective privacy protection framework needs to be able to adapt to emerging trends and advances in information management...having laws that are responsive to new and changing conditions of information handling...We must have laws that are flexible enough to handle change, but specific enough to effectively safeguard personal information (Curtis, 2007).

The purpose of the privacy framework is therefore explained as establishing parameters within which organisations and health professionals develop their own policies, protocols and other self-monitoring arrangements: 'We have a sturdy *root-system* of law and a firm and far-reaching *branch* of cross-border cooperation' (Curtis, 2007 p. 6). To this end privacy commissioners and other officials are represented as neutral arbiters, providing advice and guidance on policy, raising awareness through education and information dissemination, and monitoring compliance through audits and retrospective investigation of complaints.

5.2.2 Focus on consumer control

The literature, while premised on the understanding of privacy as a relative right, emphasises the interests and power of the consumer. The mechanism of informed consent is represented as enabling consumers to exercise a considerable degree of control over the collection and sharing of their personal

health information: ‘A health service provider generally needs your consent before they can collect your health information’ (Office of the Australian Information Commissioner, 2012). At the same time, the individual’s right to control the use and circulation of their personal information is accompanied by the expectation that they are also responsible for managing access to their personal information. ‘It is crucial that individuals take steps to secure their personal information. They are empowered to protect their own privacy’ (Curtis, 2007, p. 11). When discussing the management of requests for access to personal health information, the official literature, particularly where directed towards consumers, is consistently reassuring. It emphasises that individual privacy is paramount except in specific, clearly delineated circumstances where use or disclosure is reasonably necessary (Office of the Australian Information Commissioner, 2012):

The Office believes that the public interest in using personal information for health research should clearly or substantially outweigh individuals’ privacy interests before that information can be released without consent (Solomon, 2008).

Circumstances that are reasonably necessary are explained and justified in terms of ‘public interest’, ‘public good’ and ‘public safety’. As with privacy, these terms are not specifically defined but are constructed as fluid and amorphous. ‘Public interest is referred to but not defined in legislation. What constitutes the public interest at any time will depend on particular contexts and perspectives’ (Law Reform Commission NSW, 2001).

5.2.3 Trust

The official literature emphasises the positive outcomes of information sharing in terms of ‘benefits for all’, ‘improved health outcomes’ and ‘greater efficiency in health care delivery’. There is an emphasis on ‘trust’ and ‘confidence’ as the documentation stresses that those involved in the use of personal health information acknowledge and accept the importance of meeting

community expectations and that any exceptions to health privacy protections are well considered and transparent. ‘Consumers can reap the benefits knowing that their privacy will still be protected’ (Australian Health Ministers Advisory Council, 2009). Research findings are used to reinforce the perception that consumers can have confidence, at least in the health care sector, that their privacy is protected:

According to community attitude research conducted for the Office last year, 91% of respondents said they trusted the health sector when it came to handling their personal information. The Office tries to reinforce this trust by producing guidance for the sector and giving advice on good privacy practice (Solomon, 2008).

The apparent willingness of consumers to share their information is complemented by the representation of other stakeholders as trustworthy and responsible when seeking access to personal health information. This is expressed in discussions which emphasise ‘the collaborative relationship of trust’ (Solomon, 2008) between the various stakeholders. The response of the Privacy Commissioner to the CAMM case shows how this is conveyed:

I chose to investigate. I’d like to acknowledge the co-operation received; both organisations appear to take privacy seriously and are to be commended for this. I think that the companies co-operated very well with my office (Crompton, 2005).

The perception of trustworthiness and good intent is reinforced in publications which suggest that breaches of privacy are more often the result of lack of understanding than of deliberate attempts to evade the privacy framework. Case notes published by the Commissioner ‘provide illustrations of the various ways in which organisations, through error or misinterpretation, may breach provisions of the Privacy Act 1988 (*Cwtlh*)’ (Office of the Australian Information Commissioner, 2012).

5.2.4 Shared goals

The success of the self-regulatory approach is explained as arising from a shared understanding of the purpose and goals of the privacy framework, particularly the conceptualisation of privacy as a relative right. ‘People appreciate that other interests often come into the balance’ (ALRC, 2008a). As the 2008 International Survey on Privacy and Surveillance indicated, this representation is not unfounded. Overall, the official view is that the privacy framework works well but requires ongoing monitoring and adjustment. These adjustments, rather than seeking to make significant changes, are for the purpose of streamlining the framework to ensure clarity and consistency (Curtis, 2007; Skene, 2008; Solomon, 2008):

While submitting that the Privacy Act has generally worked well in protecting privacy and allowing appropriate information flows, the Office has strongly endorsed making privacy laws in Australia consistent so that business, government and individuals can easily understand their rights and responsibilities (Office of the Federal Privacy Commissioner Newsletter, 2008).

The language of consensus within the official literature tends to underplay the role of power and politics in establishing an appropriate balance between privacy and secondary uses of personal health information. Yet Rule argues that ‘any change in patterns of appropriation or access to personal information cannot but raise power issues – much as the official language may seek to downplay them’ (1992).

5.3 Critical commentaries

Critical analyses do not argue that personal health information should not be used for secondary purposes. They acknowledge that significant benefits can accrue from such uses (Carter, 2000a; Clarke, 2003; Greenleaf, 2007a). Many also view the Australian privacy framework as a positive and well-intentioned approach to achieving the balance between the rights of individuals to protect their personal information and the rights of other groups and the community to

use that information for legitimate purposes (Clarke, 2001; Skene, 2008; Solomon, 2008). Critical analysts, however, do question the representation of the framework as operating on the basis of cooperative, equal partnerships by drawing attention to the political manoeuvrings and differential influence of stakeholders in the interpretation and application of the privacy framework. Where official discussion is couched in terms of ‘collaboration’, ‘partnership’, ‘public interest’ and ‘trust’, these commentaries speak of ‘conflict’, ‘competing interests’ and ‘function creep’ as they explore power differentials between individuals and groups seeking either increased protection or expanded uses of personal health information (Clarke, 2006; Jacobs, 2006; Ruschena, 2008). Much of the critical discussion focuses on practical issues and incidents to do with the implementation of the framework. While there is some discussion around the interpretation of concepts, these are essentially pragmatic, focusing on the immediate concerns, rather than being located within a theoretical framework that explores the broader issues of power and influence in the construction of the privacy framework and the concepts around which it is constructed. The to and fro of debate therefore occurs within the parameters of the privacy framework, implicitly accepting its construct of a privacy/public interest balance. However, a minority do challenge the assumptions on which the privacy framework is based.

5.3.1 Practical Critique

5.3.1.1 Equal Partners?

Critics challenge the representation of stakeholders as equal partners. They particularly challenge the view of empowered consumers, arguing that the consent mechanism may not necessarily empower consumers to the extent implied in the official literature (Bygrave, 2001; Crompton, 2001). ‘Where the service is a fundamental of life (job, health service, housing, food), the individual may feel coerced into providing personal information or consenting to its use and disclosure’ (Crompton, 2001, p. 8). They also argue that the lack

of provisions for complainants to take legal action if privacy has been found to be breached reduces the power of consumers (Greenleaf, 2009; Swartz, 2005). The ALRC has thus suggested a national approach, founded on a single set of Unified Privacy Principles (UPP) and featuring a statutory cause of action for invasion of privacy (2008b).

The power of the Privacy Commissioner in relation to other stakeholders, particularly governments and their instrumentalities has also drawn comment. The official literature represents the Privacy Commissioner as having the power to effectively manage competing interests and to monitor for instances of function creep and other problematical uses of personal health information. This is challenged by critical analysts who argue that the emphasis on co-regulation and best practice limits powers of enforcement. In addition, there is no mandatory requirement for breaches of personal information to be reported, perceived breaches of privacy are dealt with on the basis of retrospective complaints, the Commissioner is only able to make formal determinations in relation to complaints that have been investigated and these determinations are not legally binding (Australian Medical Association, 2005; Greenleaf, 2009; Swartz, 2005).

The enforcement process is generally complaint driven. The Federal Privacy Commissioner has no judicial powers. However, that office has wide powers of investigation. The approach is one of conflict resolution (AMA, 2002).

Critics also note that the Privacy Commissioner only has the power to investigate complaints that fall within the parameters of the privacy framework (Swartz, 2005; Greenleaf, 2009). Thus, in the CAMM Pacific case, the issues did not come within the jurisdiction of the Privacy Commissioner because the data in question was defined as de-identified. Critical commentaries also draw attention to the ability of more influential stakeholders, particularly governments or their instrumentalities, to influence or circumvent the privacy framework (Fernando, 2009a, Greenleaf, 2006). The NSW Healthelink

electronic records project illustrated this: ‘It was against the law, so the Department of Health arranged for the State’s privacy laws to be relaxed to enable it to proceed’ (Clarke, 2009). This was considered to be a ‘direct departure of a fundamental tenet of the NSW Health Privacy Act (2002) that patients would be asked for their “express consent” before their records were included in the proposed state-wide network’ (Fernando, 2009c).

5.3.1.2 Consumer control?

Critical analyses challenge the representation in the official literature that consumers have control over the collection and use of personal information. They question the model of consent on which the framework is based, arguing that the requirement that consent must be informed, voluntary and specific is based on the traditional one-to-one relationship between doctor and patient where the primary use of information is for clinical treatment (Longstaff, 2005; Magnussen, 2008; Skene, 2008). The official documentation appears to acknowledge this, stating that ‘where there is open communication and information sharing between the health service provider and the individual, consent issues will usually be addressed during the course of the consultation’ (Office of the Federal Privacy Commissioner, 2012). Critics argue that this model does not operate well within the contemporary health care environment. Clinical care is no longer a one-to-one process and secondary uses of information are increasingly common. They suggest that the model outlined in the official literature implies that consent should be sought each time information in a record is accessed, added to, or requested for secondary use. This is considered unworkable, while suggested alternatives, such as relying on implied consent, are also criticised on the basis that in many instances implied consent can incorporate secondary uses that may not have been initially identified (Australian Privacy Foundation, 2006; Dearne, 2006; Electronic Frontiers Australia, 2006).

It should not be possible to rely on (in effect mandatory) acceptance of general terms and conditions of applying for a Medicare rebate to give consent to an unlimited range of data sharing, matching and linkage of health information with Medicare Australia (Waters, 2009).

In recent years, the potential has emerged within the public health area to be able to collect data about chronic diseases outside the context of a research study and thus without the need to obtain any individual patient's informed consent. These incidents are increasingly linked to discussion about the potential for function creep (Ball & Wood, 2006; Carter, 2000b).

5.3.1.3 Shared Goals?

While they accept that there may be consensus regarding the broad goals underpinning the privacy framework, critical discussions point to evidence of secondary or latent goals that may not always be in the interests of all stakeholders (Longstaff, 2005; Marx, 2005; Shaw & Greenhalgh, 2008).

The Foundation believes that privacy interests of the majority are too often sidelined by other interests. Every exemption shoots a hole through the safeguards provided to consumers. These should not be granted just because a self-interested lobby group demands a special deal (Australian Privacy Foundation, 2000).

While the pursuit of secondary goals is often attributed to profit-minded commercial entities, critics point out that 'researchers and other parties with "legitimate" public interests, who are often vehement in propounding the importance of their activities' may also have secondary goals when seeking access to personal information (Longstaff, 2005). The existence of secondary goals leads critics to challenge claims in the official literature of widely shared benefits accruing from secondary use of personal health information. Clarke argues that 'on balance, it is likely that patients have something to gain, but not as much as might be suggested. Third parties on the other hand, have a great deal to gain from the consolidation of patient data' (2001, p. 2), while the

Australian Privacy Foundation suggests that ‘Health e-Link (the NSW electronic health records project) is primarily for the benefit of administrators and researchers’ (APF 2009). The concept of function creep is often used to explore the agenda behind secondary or latent goals of stakeholders. These critics argue that secondary goals may result in personal health information being utilised in ways not envisaged by the legislation and which may not necessarily be in the interests of either the individual or the wider community.

5.3.1.4 Light-touch legislation: Flexibility and responsiveness?

In response to the rationale that ‘we must have laws that are flexible enough to handle change, but specific enough to effectively safeguard personal information’ (Curtis, 2007), critical analysts argue that a soft-touch approach creates ambiguities, uncertainties and provisions that create the potential function creep (Clarke, 1997; Crompton, 2001). The Victorian Privacy Commissioner, Helen Versey observed:

I am simply pointing out limits to the right to privacy which leaves it vulnerable to being eroded by other laws. The balance is fragile. Just because rights are protected does not mean that they won’t ever be abused (Versey, 2007, p. 15).

Much of the debate has focused on the interpretation of concepts that underpin the legislation and its implementation. Many of these concepts are broadly defined or are circumscribed by exceptions that render them ambiguous and contestable. This uncertainty sees the concepts regularly tested by both government and private organisations and agencies. Examples previously referred to include the Australian Sports Anti-Doping Authority (ASADA) attempt to access athletes’ prescription records and the *CAMM Pacific* case which saw the company seeking to harvest de-identified data. The Australian Sports Doping Authority was initially advised by the Australian Government Solicitor (AGS) that there were no legal impediments to the pilot taking place. This decision was later revised, with the AGS concluding that the pilot program did not have appropriate legal authority (ASADA, 2008). The *CAMM Pacific*

case centred on the distinction between identified and de-identified data. Yet this distinction is contested, with the argument that seemingly innocuous de-identified information is still contentious:

The fact that a person was treated in a particular hospital or location, such as a prison or sexual health centre, could indirectly reveal information about that person. Therefore, even though summary information such as name of hospital and health provider may not appear to be 'health information' as such, to the extent that it reveals something about a person's health status it may need to be treated with the same sensitivity as other health information (NSW Ministerial Advisory Committee on Privacy and Health Information, 2000: 11)

While the official literature argues that light-touch legislation is the best approach to managing the multifaceted and increasingly diverse information management environment, the lack of clear definitions of concepts underpinning the framework is considered to create ambiguities and uncertainties. These enable information to be utilised in ways not envisaged by the legislation, and that may not necessarily be in the interests of either the individual or the wider community (Carter, 2000a; Clarke, 2003; Greenleaf, 2007a).

Underlying many critical commentaries are concerns regarding the potential for expanding secondary uses of personal health information to result in both intentional, and unintentional discrimination towards some individuals and groups (Carter, 2000a). Yet these discussions generally remain within parameters defined by Armstrong as 'relying only on rules and laws, which tell us what should or should not happen' (2003) rather than on what can and cannot happen. This restricts their ability to explore and explain the dynamics involved in defining the problem and establishing parameters within which solutions can be identified, leading Lyon to suggest that 'the politics of privacy misses the point in some significant respects' (2007a, p.33).

5.4 How far 'to-and-fro'?

The privacy framework, which is intended to objectively manage issues related to the use of personal information, is the subject of regular commentaries and criticism. These criticisms primarily relate to the efficacy of the legislation and related policies, protocols and procedures, with official documentation explaining, justifying, and at times acknowledging limitations of the framework, and critics pointing to shortcomings and possible misrepresentations while also acknowledging the strengths of the legislation and related measures (Clarke, 2006; Jacobs, 2006; Ruschena, 2008). Both official commentaries and the critiques agree in principle that secondary use of personal information has benefits. The official literature emphasises the collaboration, partnership, public interest and trust involved in using personal information while the critiques point to the need to consider competing interests, function creep, and power differentials. Thus, the arguments by Bygrave (2001) and Crompton, 2001) that the consent mechanism may not necessarily empower consumers to the extent implied in the official literature and the observations by (Swartz, 2005) and Greenleaf, 2009) regarding the capacity of the Privacy Commissioner to investigate only those complaints that fall within the parameters of the privacy framework. These discussions occur largely within the established parameters of the privacy/public interest construct. They do not challenge the dominant understanding of information management issues in terms of individual privacy, or the construct of this concept almost exclusively in terms of a private/public interest balance. The sociological analysis adopted in this study offered the opportunity to challenge these constructs by exploring the interplay between power relationships in the social world and understandings about personal information issues. The analysis, drawing on Foucault's arguments about the relationship between power, knowledge and discourse, focussed on how these constructs came to dominate and conversely, what alternative constructs were excluded or marginalised. In doing so the analysis links the use of personal health information to broader social practices

of surveillance, while identifying health informatics as a claim-making site that produces discourses that shape understandings about the use of personal health information.

5.4 Conclusion

Debate about the efficacy of the Australian privacy framework emanates from institutional sites including governments, instrumentalities with the authority to oversee the framework, the law, educational and research institutions and consumer and commercial organisations. Within these sites, acknowledged experts determine the appropriate development of frameworks and systems to manage the collection and use of personal health information. They are able to do so because they are perceived to have expertise that the wider population does not have. This claim to expert knowledge enables these groups to exercise power to shape the way the issues are understood and to determine appropriate strategies to manage them. In doing so, these experts increase their legitimacy, whilst others are silencing and de-legitimising other perspectives (Biggs, & Powell, 2001). This power/knowledge struggle within the claim-making site was the focus of the next phase of the study. Chapter 6 describes the discourses identified within the academic discipline of health informatics, noting the focus, themes and status hierarchies that distinguish each from the other. A significant finding was the lack of a critical discourse within the texts. Chapter 7 traces the emergence of each discourse in local institutional sites, noting how more influential discourses expanded and coalesced to the point where they are currently accepted as the appropriate disciplinary knowledge, or regime of truth. Less influential, subjugated and marginalised discourses are also noted. Chapter 8 focuses specifically on the way the discourses construct issues around the use of personal health information. The analysis noted that all discourses accepted the boundaries established by the privacy framework. This manifested in limited acknowledgement of function creep, particularly the

occurrence of legal exceptions and other strategies that facilitated expanded uses of personal health information.

Chapter 6: Health informatics discourses

6.1 Introduction

This chapter is the first of three that address the main focus of the study: to identify health informatics discourses and their relative influence on shaping the academic discipline's approach to issues of personal information management. This chapter addresses the first question of the study: *What discourses can be identified in the discipline of health informatics?* It does so by describing the discourses identified in the conference texts. This analysis is preceded by a brief historical narrative which represents the accepted view of the development of the discipline. This narrative was developed by referring to documentation within the health informatics literature, primarily histories of the development of the discipline. The narrative represents health informatics as evolving from diverse disciplinary beginnings to become an integrated academic discipline. The discourse analysis challenges this representation,

The documents for this phase of the analysis were drawn from Health Informatics Society of Australia (HISA) national conference proceedings. The health informatics community in Australia is relatively small. There are few professional organisations and/or official publications. HISA, established in 1992, was the first health informatics organisation in Australia. Today it is one of two peak bodies, the other being the Australasian College of Health Informatics (ACHI). HISA has hosted the national conference every year since the inaugural conference of 1993 and this is a primary means of communication, discussion and information dissemination for the field. The conference attracts a wide range of health, computer science and health informatics professionals, together with industry and government representatives. It was viewed as a forum where discontinuities, innovations, contradictions, comparisons and transformations would appear. The study

focused on identifying discourses through ‘the delimitation of the field of objects, the definition of a legitimate perspective for the agent of knowledge, and the fixing of norms for the elaboration of concepts and theories’ (Foucault cited in Hoy, 1986, p. 122). This was an iterative process as previously outlined in detail in Chapter 3.

Foucault argued that ‘archaeology concerns the pure description of discursive events’ (Foucault, 1991a, p. 59). Therefore, the discussion of discourses is descriptive, rather than analytical. It describes the focus, themes and subject positions that differentiate the discourses. While this description incorporates many statements from individual authors, it is not the intention to attribute these individuals with particular insights about the discourse. Foucault emphasised that subjects are not the initiators of discourse (James, 2004, p. 17) but that discourses determine who experts are and what they can say. As Schneck observes, ‘knowledge obtained and emanating from a subject is not so much a reflection of independent will or “single intentional agent”, but rather of a larger, all-encompassing framework of statements more enduring than that of individual statements’ (1987, p. 18). While comments in the analysis have been attributed to specific authors, this is for the purposes of confirmability and auditability around the methodology, rather than to individualise and attribute status to particular authors.

6.1.2 Health informatics: the historical narrative

Foucault wrote ‘genesis, continuity, totalisation: these are the great themes of the history of ideas, and that by which it is attached to a certain, now traditional, form of historical analysis’ (1972, p. 136). The historical analysis of health informatics reflects these themes. Musen and van Bommel encapsulate this in their statement that ‘during the past three or four decades, we have transitioned from a group of hospital-based technologists whose primary focus was the implementation of clinical information systems to a diverse community of scholars, clinicians, engineers and pragmatists’ (2003, p. 209). Other

commentaries support this representation, depicting health informatics as evolving into ‘a unified, scientific discipline with a strong academic program and professional identity’ (Musen & van Bommel, 2003). Use of terms like ‘infancy’ and ‘mature science’ (Clarke, 2001; Friedman & Abbas, 2003) and references to ‘building’ the theoretical and research base to enable the discipline to ‘move ahead’ (Lindberg, 1987; Lorenzi et al., 1997; Musen & van Bommel, 2003) emphasise that this is a continuous, progressive and cumulative process. While different, even conflicting views about the scope and focus of health informatics are acknowledged, they are interpreted as characteristic of an emerging discipline that will be resolved as it reaches maturity (Patel & Kauffman, 1998; Tolentino, 1999; McKenzie, 2000; Georgiou, 2002; Coiera, 2003). Overall the historical narrative creates a sense of progress and of the coming together of a united scientific community. In doing so, it emphasises ontological and epistemological issues, with discussions focusing on the disciplinary characteristics of health informatics, the relevant ontologies and problem solving methodologies and the need to identify broad, domain-independent, even culturally neutral, underlying principles that will provide coherency to research programs (Walker, in Hovenga et al., 1997; Musen & van Bommel, 2003; Musen, 2002; Conrick, 2006). Underpinning much of the discussion is the assumption that the development of health informatics knowledge is value free, that ‘truth or the search for truth operates, at least in its ideal form, outside the play of power and politics’ (Introna, 2003, p. 236).

Yet rather than coalescing into a single unified perspective, diverse views within the discipline have been an enduring feature of disciplinary discussion. More than a decade ago, Morris and McCain conducted a systematic analysis of health and medical informatics journals and found that ‘despite indications of a core literature and several major research fronts, there is a clear dichotomy between the scientific and the social scientific orientations’ (1998, p. 447).

These different orientations focused on different issues and approaches to resolving these:

Medical informatics journals indexed in the Science Citation Index (natural sciences, engineering and medicine) placed more emphasis on computers, engineering and theory, while journals indexed by the Social Science Citation Index (social sciences) emphasised decision-making and the application of the discipline to practice (Morris & McCain, 1998, p. 447).

Commentaries since this analysis suggest that the health informatics community is even more complex and diverse than the science/social science dichotomy suggests. The 2003 *International Medical Informatics Association Yearbook* devoted an entire section to exploring the nature of health informatics, with Musen and van Bommel arguing that ‘we need to define our paradigm and to demonstrate how our research collectively builds on a common theory’ (2003, p. 195). More recently, Hersh noted that ‘the terminology of health information technology, as well as biomedical and health information, is poorly understood and not even agreed upon by academics and professionals in the field’ (2009, p. 1). Hales described these discussions as ‘turf wars’ where groups ‘seek to shape and constrain the practice of health informatics according to their views’ (Hales, 2000). From a Foucauldian perspective these turf wars may be understood as discourses seeking to define what is regarded as knowledge and how it should be organised. Turf wars do not take place at the level of ontological or epistemological discussion, but occur at the political level. ‘The status of an academic discipline is not an ontological or epistemological question but rather a political one from the start’ (Introna, 2003, p. 236). From this perspective, the historical narrative becomes ‘one particular interpretation of truth within a historical and cultural context,’ (Manias & Street, 2000b, p. 56). The discourse analysis challenged the historical narrative, pointing to alternative understandings of health informatics knowledge and knowledge development processes.

6.2 Health informatics discourses

One possible starting point for discovering the health informatics discourses was to begin with discourses identified in earlier studies. Since discourses are not self-evident, the use of previously identified discourses had the advantage of creating some structure or guidance in a complex process. At the same time, the use of predetermined discourses had the potential to impose parameters which might result in marginal or unspoken discourses being overlooked (Sharp and Richardson, 2001). This is especially problematic where relevant discourse analyses are limited and focus on a sub-set of the field, as was the case with this study. As discussed in Chapter 2, a review of the literature found limited discourse analysis research within the field of health informatics. Those that were found focussed on specific applications of health informatics technologies such as telehealth or e-health rather than the broader knowledge development and dissemination processes of the academic discipline (Klecun-Dabrowska & Cornford, 2000; Cornford & Klecun-Dabrowska, 2003; Horsfield & Peterson, 2000). The Horsfield and Peterson study the only Australian study located, also identified discourses shaping the diffusion of telehealth across health services. As noted previously, Foucault argued that the formation of a discourse is ‘always determined in the time and space that have defined a given period and for a given social, economic, geographical, or linguistic area’ (Foucault, 1972, p. 115). Therefore, unique historical, cultural and political contexts shaped Australian health informatics discourses. The Horsfield and Peterson study focussed on the same context as this study and therefore offered an appropriate starting point for this analysis. The discourses identified by Horsfield and Peterson are listed in Table 6.1.

Table 6.1: Telehealth discourses identified by Horsfield and Peterson

Discourse	Description
Consumer	This discourse constructs the individual as active participant in his or her own health care.
Critical	The discourse uses the language of ideology, domination, inequality and hegemony and discusses health informatics as a social construct around issues of power and control.
Pedagogic	Concerned with strategies to ensure that education and scholarly debate in the use of information and advanced technologies in health care can proceed with clarity and a common purpose
Medical practitioner	This discourse uses the language of patient care and patient outcomes (Horsfield and Peterson, 2000: 7). It represents the view of the health professional.
Information technology as progress	The discourse, states that the specific capacities of the technology can, do, and should drive reform and changes in social and institutional practices
E-health as commerce	This discourse is concerned with business expansion and commercial development.

(Source: Horsfield & Peterson, 2000, pp. 8-10)

An alternative approach was to begin the analysis without preconceived or pre-existing discourses, allowing the discourses to emerge through the detailed analysis of the texts in the field of study (Sharp and Richardson, 2001; Quibell, 2004). This latter approach addresses the limitations of using predetermined categories, but opens the process to the influence of the researcher's interests and preoccupations (Sharp and Richardson, 2001, p.203). This study sought to exploit the advantages offered by both options, using pre-existing discourses described by Horsfield and Peterson as a guide for identifying characteristics of discourses within the health informatics documents, but moving beyond these as the analysis progressed.

The initial reading of the texts to identify the way the object of knowledge was constructed saw the delineation of discourses begin. While the description of health informatics as focussing on the collection, storage, manipulation and dissemination of health information appeared frequently in the texts, this focus was qualified by the use of descriptors such as *nursing*, *clinical*, and *management*. This pointed to some broad differentiations. As the iterative reading of the texts proceeded, these differentiations became clearer as groups

of statements linked objects with subject positions and conceptual architectures that structured discussion. This is illustrated in the following statements:

- A major goal in a modern health care system is to represent the state of a patient's health and the health of a community in a way that is useful for automatic processing by computers (Ellis, 1993)
- The driving force of those systems were clinicians and the main purpose was to support clinical practice (Jayasuriya: 1993)

The first statement prioritises *technology* (computerised order entry systems) allocating it a central role in shaping the behaviour of clinicians and in managing effective and efficient health care. The second statement links the concepts in such a way as to create an intrinsic opposition to the former representation. In this statement, technology was subordinate to the information management requirements of clinicians. As the reading of the texts progressed, linkages around the object of knowledge, recurring groupings of subject positions or consistent progressions of concepts became clearer. In this way, the discourses emerged from the texts.

It was clear, from the very early stages of the analysis that the discourses appearing within the conference texts did not correspond with those described by Horsfield and Peterson. In particular, the consumer discourse, the medical practitioner discourse and the critical discourse were not identified (2000, p. 6). This may be partly explained by the way the discourses were named in the respective studies. This study adopted the Foucauldian view that 'subjects are not the initiators of discourse, but are simultaneously the products of discourse and a means by which discourses are propagated' (James, 2004, p. 17). Therefore, discourses were named to reflect their specific focus and concerns within the academic discipline, and to indicate possible connections or synergies with other discourses external to the discipline, while subject positions were located within specific discourses. In this study, the consumer was identified as a subject position, primarily in the management discourse

rather than as a discourse in its own right. Other discourses used alternative constructs for this status. These included ‘patient’ in the clinical informatics and nursing informatics discourses and ‘user’ in the health technology discourse. Similarly, the medical practitioner was a subject position within the clinical informatics discourse, but alternatively constructed as ‘nurse’, ‘health professional’ or ‘user’ in other discourses. With regard to a critical discourse, while a number of statements in various texts pointed to critical opinions expressed by some individuals in diverse locations, this analysis identified no critical discourse, or even critical theme within discourses.

This analysis identified six discourses. These were initially indicated by the way the object of knowledge was constructed. Since the discourses were located within the discursive field of the discipline of health informatics, it was expected that some terms delineating the object of knowledge would be shared. This proved to be the case. However, the analysis also noted particular terms which occurred in specific contexts or in reference to specific activities but not in other contexts. For example, descriptors such as *nursing* or *clinical* appeared in some discussions but not others. Such terms pointed to a delineation and demarcation between discourses. Contexts in which these terms appeared, endured or disappeared were noted. Contexts included pre-existing fields such as the academic environment of a reference discipline, a commercial context, or health situation, or new fields such as a newly emerged health informatics academic program, or a health technology department.

Synergies between different conceptual architectures and status hierarchies were considered. For example, the recurrence of subject positions such as *clinician* and *patient* in statements where a conceptual architecture subordinated technology to the information management requirements of clinicians, or the regular reference to effective resolution of information management issues and challenges through the activities of *health informatics researchers*, and

informatics professionals. This enabled a more confident differentiation between discourses. The delineation of discourses was further progressed by identifying the enunciative modalities associated with subject positions. For example, a pattern was noted where ‘technology experts’ were institutionally located within departments of computing or information systems, or health organisation technology divisions. The authority of ‘nursing informatics professionals’ was linked to both nursing and health informatics qualifications, while the authority of the emerging ‘health informatics academic’ came to be associated with health informatics qualifications. The incorporation of conceptual architectures and status hierarchies into identifiable themes enabled discourses to be more strongly identified and described. Themes and theories contributed the final element in the delineation of the discourses. The analysis looked for links between recurring themes and theories. Discourses were differentiated by noting links between elements identified in the texts. Thus, recurring themes utilising the same conceptual architectures and status hierarchies to speak of a particular object of knowledge, delineated a discourse.

The discourses were named to reflect their specific focus and concerns within the academic discipline and to indicate possible connections or synergies with other discourses external to the discipline. The names allocated to the discourses identified in this study were:

- Scholarly discourse: The scholarly discourse was named to reflect its aspirational goal of establishing health informatics as an academic discipline.
- Management discourse: The management discourse echoes the themes of economic rationalism and new managerialism, dominant discourses of modernity.
- Health technology discourse: This discourse was named to indicate its focus on information technology while differentiating it from more

generic technology discourses, including the disciplinary discourses of computing and information systems.

- Populations discourse: This discourse focused on the collection and use of aggregated data for research, service planning and evaluation and public health. While it has synergies with public health discourses, it has a broader scope than this discipline. The name ‘populations’ is intended to convey this.
- Clinical informatics discourse: This discourse primarily reflected the issues of medical professionals.
- Nursing informatics discourse: The discourse focused on nursing, nursing practice and information management in nursing.

The next section of this chapter describes these discourses in detail. The focus, themes and strategies and subject positions and status hierarchies for each discourse are delineated.

6.2.1 Scholarly discourse: An academic focus

Focus

Within the scholarly discourse, the focus of health informatics encompasses the people, processes, technology and environments of health information management. This was indicated in recurring statements that constructed health information management as the use of technology and information systems to enable health professionals and health care organisations to provide cost-effective, efficient services that result in quality patient outcomes. Yet while the discourse discussed the practical aspects of information management in the health care environment, there was a strong focus on academic issues and questions. Recurring statements emphasised that effective resolution of information management issues and challenges in the health care environment would be best achieved through the accumulation of a formal body of

knowledge to inform the practice of appropriately accredited health informatics professionals. An aspirational goal of the scholarly discourse was to establish the discipline of health informatics as the acknowledged authority for the production, dissemination and application of knowledge. Achieving disciplinary status was represented as a milestone for the advancement of health informatics. The Foreword of the proceedings for inaugural health informatics conference hinted at this inspirational goal:

- The objective of this conference was to explore ways of using information technology in the health sector towards promoting health, providing cost-effective, quality health services, structuring professional knowledge and increasing this knowledge through research (Hovenga, 1993, Foreword)

The call for a distinct discipline was justified by emphasising the uniqueness of health informatics knowledge and practice:

- These conditions cannot be satisfied unless there is a cadre of appropriately qualified, competent and experienced information and IT staff in healthcare organisations...who need a standardised set of skills, competencies and knowledge...a planned approach to education and training for information work in health services is required urgently (Brittain, 1993)
- There have been mistakes, wasted resources. These mistakes are due to a lack of understanding. Expertise will eliminate mistakes of the past (Brittain, 1993)
- The aims of this course are to develop a distinctive course that builds upon the special expertise in health informatics (McPhee et al., 1999)
- The specialisation of health informatics provides a critical understanding of the ways in which IT has reshaped thinking and practices (Sahama, 2009)
- Researchers are in the best position to fulfil the role of intermediators between technologists and clinicians (Wong & Yee, 2006)

A number of strategies operated to confine activity within academic parameters. In conference papers, health informatics was variously described as a 'discipline', an 'academic discipline', a 'science' and a 'scientific discipline'.

These papers explored academic issues and questions, emphasising that effective health information management would be best achieved through the accumulation of a formal body of knowledge to inform the practice of appropriately accredited health informatics professionals:

- Informatics will be able to contribute much more effectively to health services if it incorporates an understanding of knowledge processes (Southon & Cook, 2001)
- The research aimed to produce a set of design principles and guidelines for the development of mobile information technologies (Kelder et al., 2008)
- This study adds depth to the understanding of the role of cultural, environmental, and human factors, alongside insights into how complex, dynamic, multi-faceted interactions amongst all factors can influence clinical handover outcomes (Turner, 2006)
- The overall objective is to develop a theoretical model for analysing healthcare software for better quality healthcare services (Wong, 2009)

The lack of research and theoretical discussion was highlighted, the need for rigorous research and evaluation was stressed and there were calls for consensus in approaches to health informatics teaching and the research agenda. Intellectual rigour was reinforced by critiquing practices which did not conform to academic standards. Statements created an ‘us and them’ environment by contrasting the emerging health informatics community with earlier approaches to health information management. The former was positioned as superior, offering objective, reasoned, approaches to explain and guide information management in the health care environment. The health informatics community was described as comprising ‘contributors’, ‘members’ and ‘knowledgeable people’ who were motivated and united in their agreement about the need for a cohesive approach to knowledge production and professional practice:

- There was strong support for the principle of developing a unified, national health informatics organisation. Such an organisation would seek to structure professional knowledge and increase this knowledge through research (Hovenga, 1993)

In emphasising the validity of academic knowledge production, the discourse expresses regret that some continued to follow the inefficient, ineffective or out-dated practices of the past. Those who sought to follow past practices or who resisted academic practices were represented as misguided or out of touch. This made resistance to the discourse difficult:

- Previous practices are associated with inappropriate, inadequate practices and seat of the pants management (Brittain, 1993)
- There are those who cannot conceptualise how health service providers and consumers would benefit from IT in health and there are others who are frustrated at the slow uncoordinated progress made (Hovenga & Whymark, 1993)
- IT and computer applications in health care are well-known to be a black hole (Brittain, 1993).
- Many information systems have been user-unfriendly, some systems have been over-engineered, accuracy of data has suffered...there is 'techno' and 'computer speak' (Brittain, 1993)
- Unfortunately this group chose not to participate (Hovenga, 1993)
- There is considerable resistance especially from older and established clinicians (Brittain, 1993)

Underpinning the scholarly discourse was the truth claim that academic knowledge is a superior form of knowledge. Statements linked health informatics to academic practices thereby establishing its credentials and associating itself with the 'intellectual rigour' which provides a privileged source of truth (Foucault, 1980). At the same time, the discourse sought to differentiate itself from related academic disciplines, arguing that the uniqueness and complexity of health care and health information required a specific discipline distinct from the existing information management disciplines. An implicit dualism represented the social and organisational characteristics of health care environments as significantly more complex than the business and commercial environment:

- The hospital environment is 20 times more complex than a manufacturing environment (Thom & Chu, 1993)
- The health industry is unique in its information needs (Jane, 1999)
- The slow uptake, historically, of IT in health has been due to the volume and complexity of healthcare data (Hovenga & Whymark, 1993)
- There is a lack of in-depth understanding of the delivery model of medical care (Wong & Yee, 2006)

The distinctiveness of the health care environment was further emphasised by contrasting the data used in financial and administrative systems with biomedical knowledge. The former was constructed as uniform and easily structured for use in information systems, while biomedical knowledge was represented as *imprecise, open to interpretation and not easily structured, organised or manipulated*. Consequently, the scholarly discourse rejected the approach adopted by existing academic information management disciplines as inadequate. Health information management required specialised knowledge and skills:

- Health authorities need a new type of 'hybrid' manager; a person in a position of authority (Brittain, 1993)
- Information workers need an understanding of health services, including organisational theory and the structure of health services, legislation dealing with health care which affects information provision, including consideration of special requirements for information management in the health services; generic aspects of information systems, an emphasis on health service applications (Brittain, 1993)
- Difficulties in communication between technologists and clinicians...lack of in-depth understanding of the delivery model of medical care...researchers are in the best position to fulfil the role of intermediators between technologists and clinicians, through suggesting a medico-techno-info-social integrated solution (Wong & Yee, 2006)

Emphasising academic knowledge production served to marginalise anecdotal descriptions, reflections and personal opinions that are evident in some other discourses. Within the scholarly discourse, health informatics becomes knowable through the language and practices of academia.

Themes and strategies

The analysis identified a number of themes that established parameters for appropriate and acceptable knowledge and knowledge production processes within the discourse. These themes encompassed understandings about the concepts of data, information and knowledge, appropriate knowledge and knowledge production standards for a discipline, and the role of information technology.

Data, information and knowledge were constructed as a conceptual hierarchy: 'Health informatics, as a discipline, is concerned with the collection, storage, retrieval, communication and optimal use of health related data, information and knowledge' (Hovenga, 93). Data and information were understood as discrete entities, contained within clear boundaries. These contrasted with knowledge as uncertain, evolving, with gaps to be explored and revealed. Information technology was an efficient and effective tool for the collection and manipulation of data to produce information, but the analysis and interpretation of the data and information to create knowledge was delineated as a human activity:

- Knowledge generation is a human function (Jane, 1999)
- Medical practice thrives on individuality, personal experience and opinions (Wong & Yee, 2006)

Even where more sophisticated decision support and expert systems technology was discussed, the scholarly discourse represented humans as retaining the ultimate responsibility for knowledge development for the human expert. This

reinforced the representation of health informatics as an academic discipline responsible for knowledge production and dissemination.

Discussions advocating the imposition of academic conventions for developing and disseminating health informatics knowledge supported the academic focus of the discourse. Recurring statements emphasised the need to adopt the established practices of the academic community. Texts spoke of knowledge development as a progressive, cumulative process involving rigorous research activity. They emphasised the relevance of research findings, of building on prior knowledge and of identifying and addressing knowledge gaps:

- This study aimed to provide validation for four theoretical dimensions of information system success (Crittenden, 1999)
- The information presented in this report is only an attempt to highlight the complexity of undertaking research in this area, and is far from complete (Hardy et al., 2001)
- Little research has been done into the kinds of information needs that arise over time and during different situations in the lived experience of being an informal carer. Future research is needed to test the usefulness of this taxonomy with other groups or informal carers (Basil et al. 2008).
- This paper contributes to identifying and mapping a research gap in understanding how information systems could possibly support professional educators (Kelderet, 2008)

The discourse represented research output as forming the basis for education programs. Education programs produce the experts needed to further the discipline and profession of health informatics. Appropriate education programs were delineated with authors speaking of core knowledge, the need for common skills and the need for a shared approach to the education of health informatics professionals. 'It is timely to work towards a nationally agreed set of competencies, skills and knowledge for information workers in all facets of

health care' (Brittain, 1993). The discourse also linked academic research with professional practice. In doing so, it prioritised research:

- Anticipated benefits to patient outcomes are only likely to occur if there are significant concurrent changes in institutional knowledge, managerial, organisation and clinical cultures – current theories do not adequately reflect the approach to change needed (1999)
- An understanding of change management theory is critical to successful implementation of clinical information systems (Griswold, 1999)
- The current literature has no empirical evidence to evaluate the impact of software quality on the quality of healthcare service delivery (Wong, 2009)
- The overall objective of this paper is to develop a theoretical model for analysing healthcare software quality for better health services (Wong, 2009)

Strategies to ensure conformity to academic practices included the establishment of academic qualifications as a requirement for entry into the field, and ongoing peer review of activities once legitimacy was achieved. The emphasis on academic knowledge production served to marginalise the anecdotal descriptions and personal opinions accepted as knowledge in some other discourses. Within the scholarly discourse, health informatics became knowable through the language and practices of academia. The discourse also established parameters around 'appropriate' health informatics knowledge.

As with other discourses, the scholarly discourse focused on the broad knowledge domain of information management in health care. Recurring statements referred to computers, information technology and electronic records as the means to provide cost-effective, more effective services:

- The objective of this conference was to explore ways of using information technology (IT) in the health sector towards providing cost-effective, quality health services (Hovenga, 1993)
- The current national approach to electronic health records aims to improve health outcomes, together with a more effective delivery of health services (Hovenga, 2001)

- Computerised Physician Order Entry Systems (CPOE) have the potential to lead to improvements in the quality and efficiency of health care delivery (Georgiou et al. 2006)
- It [health informatics] can be viewed as computer applications in medical and/or health processes for developing better health solutions (Sahama, 2009)

At the same time, the discourse delineated particular knowledge as appropriate while excluding other knowledge. The representation of information technology and the conceptualisation of information and knowledge illustrate this delineation. All health informatics discourses incorporated information technology as an integral knowledge area. However, unlike several other health informatics discourses, the scholarly discourse did not privilege technology as the primary focus of information management. Although acknowledged as an increasingly superior method to manual methods of data and information management practices, technology remained a tool to be used as required by health professionals. Thus, the discourse referred to the capacity of technology to overcome the drudgery of manual information capture, but did not represent technology as the ultimate answer for all issues. This legitimised the development of knowledge encompassing more than technology issues thereby expanding discussion to incorporate social and organisational issues.

Subject positions, status hierarchy

In constructing health informatics as a distinct academic discipline, the scholarly discourse also constructed the appropriately accredited ‘health informatics specialist’ with specific knowledge and expertise. This privileged health informatics academics, students and professionals over those without this knowledge/expertise. These experts were referred to in the texts as ‘researchers’, or more specifically, as ‘health informatics researchers’, ‘informatics professionals’. They were acknowledged as members of the community ‘contributing to the knowledge development and practice.’ At the same time, the scholarly discourse acknowledged experts from other knowledge

domains, including clinical, information technology and management. For the practice of health information management, the health informatics professional was accorded a higher status position, having the key role as intermediary between other experts. Other status positions structured the users of health informatics knowledge and expertise into categories such as healthcare professionals, doctors and nurses, managers and executives, project leaders, project managers and content developers. These groups were sometimes differentiated but were frequently subsumed under the generic status of users.

- The boundary between information staff, and IT technical, computer science and systems engineering staff is difficult to draw and education and training plans must be clear. The needs of the two groups are very different (Brittain, 1993)

The need for suitably educated and accredited professionals was a recurring theme, while demonstrated academic and/or professional expertise earned the authority to speak. Those demonstrating greater expertise were accorded a more privileged status. This was seen in the designation of academic status positions within an hierarchy where the lowest status was that of student, and higher statuses were distinguished by titles Doctor or Professor. Guidelines for membership of the Australian College of Health Informatics differentiated between Members and Fellows. Fellows were considered to have made a significant contribution to the profession and were accorded a higher status than members. The highest status positions were permitted to speak on behalf of the whole community:

The Australian College of Health Informatics has the expertise to advise government and the professions on eHealth matters, in particular the national direction, implementation and support for health informatics and educational and capacity building, innovation and diffusion, standards development, research, performance and quality management (Australian College of Health Informatics, 2008)

The scholarly discourse constructed health informatics is an academic and professional activity, emphasising the need to use sound academic research

activity to inform practice. The discourse privileged the academic by incorporating academic concepts and emphasising academic research and teaching regimes. In constructing health informatics as a distinct academic discipline, the scholarly discourse also constructed the appropriately accredited ‘health informatics specialist’ with specific knowledge and expertise.

6.2.2 Management discourse: Management not treatment

Focus

As with other discourses, the management discourse was concerned with the use of information and information management systems to provide efficient and effective health care. This discourse linked efficient and effective healthcare to good management practices. The focus of health informatics was therefore the development, implementation and use of information and information management systems to support good management practices. Discussions referred to the need to share data for more informed decision-making and service planning, to reduce operating costs through efficiencies, and to reduce demands on time, money and human resources. The language of business and management established these parameters and delineated areas of concern. Rather than speaking of ‘hospitals and surgeries’, the management discourse spoke of facilities and treatment centres, while ‘clinicians’ were ‘health care providers’ and ‘patients’ were ‘clients,’ ‘consumers’ or ‘customers’. Health professionals had management responsibilities rather than clinical oversight and were responsible for individual management plans and modelling the patient journey rather than for developing treatment or care plans. Health care was conceptualised as a business or an industry and health care activities were examined and discussed in terms of ‘productivity’ and ‘efficiencies’, ‘best practice funding models’, ‘balanced score cards’, and ‘value adding’:

- As activity in the OR [operating room] contributes significantly to hospital revenue, hospital management requires extensive information on the performance of this area (Jahn, 1999)
- Patient journey redesign involves analysing the overall processes involved with the movement of a patient through the health care system. This journey can be improved via the removal of wasted and excessive activities, process duplication (Curry et al, 2006)

While this did not exclude consideration of service quality, treatments or patient care, these issues were generally linked to good management practice:

- A health care provider is any person or organisation who is involved in or associated with the delivery of health care to a client (Ho, 2006)
- A managerial approach to utilising Telehealth in the workplace is suggested (Tang-Taye & Turner, 2009)

In doing so the management discourse constructed information as a valuable commodity for informed decision making.

Themes and strategies

Themes establishing parameters for the focus of the discourse included the promotion of sound management principles as the solution to the ‘crisis of health care’, the representation of information and knowledge as quantifiable resources to support management decision making, and the representation of health care as a system.

Underpinning the discourse were truth claims about a crisis in health care. This crisis was indicated by increasing demands for services, rising costs and scarce resources resulting in the inability of services to meet demand:

- The SA HealthPlus Coordinated Care Trial was established in South Australia in late 1996 in response to a crisis in the hospital system (Harvey et al. 1999)
- One of the challenges facing health and welfare policy makers is the increasing demand for ageing services and aged care (McDonald et al., 2008)

- The Australian Federal Government spent in excess of \$40 billion on Health and Aged Care during the 2003-2004 financial year. This equals 20% of the total federal budget (Curry et al., 2006)

The crisis was attributed to traditional structures and processes of health care. These were characterised as ‘treatment focussed’ and ‘fragmented’, resulting in ‘inefficiencies’, ‘duplication of services’, ‘wasted resources’ and ‘lack of accountability’. The urgency of the problem was emphasised through use of emotive language speaking of ‘threats to the survival of health care organisations’:

- Managing these processes efficiently is now imperative for progressive societies (Unnithan, Smith & Fraunholz, 2009)
- The system is perceived to offer many benefits to currently resource critical/strained clinical environments. (Unnithan, Smith & Fraunholz, 2009)
- Representing a burden for health providers who are under the strain to help patients cope (Hobson, 2009)

The discourse represented the application of sound management principles and practices as a ‘legitimate’, ‘reasonable’, and ‘much needed response’ to this health care crisis. Integral to this representation was the assumption that health care resources were limited and must therefore be rationed. Statements referred to the need to ensure that finite, limited resources were distributed to ensure efficient use and equity of access to services

- There is an increasing need to share scarce resources more appropriately (Fitzpatrick, 1999)
- It is well documented that utilising appropriate and safe telehealth technologies can potentially reduce time, money and human resources when delivering health care (Best, 2009)
- CPOE systems have the potential to deliver substantial efficiency gains (Georgiou et al., 2008)

The crisis in health care theme provided the rationale for the discourse to introduce sound management practices as a solution. Sound management practices included establishment of 'practice standards', 'accountability' and a 'striving for business excellence'. Measures of good practice were quantified. Thus, customer satisfaction might be referred to in terms of 'wait times for services no longer than 24 hours'; effective service evaluated in terms of an 'error rate of not more than 10%; each year'; and good service delivery equated with 'financial efficiencies such as not less than 90% of the budget' or 'within 5% of budget estimates'. This justified the use of information management systems for monitoring activities, measuring outcomes, comparing performance and introducing standards and standardised practices to facilitate these activities. Underpinning these practices was the assumption that measuring performance against national standards and/or comparing individuals and organisations with each other would inevitably improve health care. This justified a strengthening of controls over the activity of the health organisation and individual practitioners:

- The health professional should be able to measure and be accountable for the quality of care they deliver (Ford & Walker, 1993)
- Development of clinical practice guidelines will improve consistency of clinical practice and support the effective measurement of outcomes (Cook, 2001)
- The CPR contains a suite of reports which allow Heads of Units to analyse the performance of their own unit, Hospital Boards to analyse the performance of their hospital and compare relative performance of units within hospitals, Regional Boards to analyse and compare hospitals within their regions (Royle & Germann, 2006)

The good management practices advocated by the discourse were contrasted with the inefficient, wasteful practices that were contributing to the crisis in healthcare. This made it very difficult to counter the management discourse, since resistance was tantamount to supporting practices linked to poor quality service and poor outcomes for clients.

Fundamental to the management discourse was the assumption that a health service is a distinct, dynamic system. This allowed the focus of the discourse to be very broad, encompassing everything within the system. This contrasted with discourses such as the clinical informatics and nursing informatics discourses with their more restricted spans of interest. Within the management discourse, people, places and processes were all component parts of the system, integral to its successful functioning but at the same time were elements that needed effective management:

- The system can be described in terms of its processes, people and technologies. Organising and coordinating these roles and people to enhance processes is an ongoing challenge for managers (McDonnell, 1999)
- The complexity of the health system should never be underestimated...the nonlinear behaviour of complex systems, the presence of competing feedback loops, and the presence of system delays are all part of the resulting complexity (Tipper & McDonnell, 2006)

Management goals were system goals. People, as parts of the system, were expected to adopt and work towards achieving these goals. Achieving system goals was operationalised in terms of efficiency and effectiveness, particularly fiscal efficiencies, while proper management of the system was constructed in terms of control, accountability, rationalisation, and resource management:

- In order to obtain maximum benefits from an imaging system, the business or organisational situation must be examined as a whole (Hoare & MacCallum, 1993)
- Process benchmarking and better practice involves a review of all business processes, clinical information practices and information requirements using a benchmarking and better practice methodology (Cook, 2001)
- Improved clinical outcomes proved difficult to measure. However the team changed the approach by breaking down clinical outcomes into measurable component parts (Forsythe et al., 2009)

Even resistance to managerial practices was conceptualised as a systems issue:

- The system will respond and attempt to stifle the change by throwing up substantial challenges to this promising growth (McDonnell, 1999)

The activities of health professionals were constructed around meeting corporate goals. While acknowledging their primary role as providers of health care, this construction expanded traditional activities to include documenting clinical outcomes for accountability purposes, meeting standardised performance indicators and contributing to the overall accountability processes of the system. In this way health professionals were involved in meeting the goals of the system while contributing to monitoring their own behaviour. Monitoring of health professionals was legitimised and normalised as essential for ensuring high quality outcomes:

- This IT network was to become the essential nucleus of an outcome based system in which careful tracking of inputs and health outcomes would result in improved healthcare and a more efficient and accountable health system (Harvey et al. 1999)
- This study used the CRR to investigate the feasibility of assessing, on an ongoing basis, whether or not clinicians were complying with established guidelines within a hospital (Royle & Germann, 2006).
- Early applications of RFID are now giving way to staff tracking, combined with time and motion studies to optimise work flows in areas such as radiology and surgeries (Unnithan, Smith & Fraunholz, 2009)

Information management issues were framed in terms of enabling the system to achieve its goals or mission:

- There must be a clear understanding at all levels of the organisation as to how information systems can support the organisation's mission...appropriateness should be considered in terms of the needs of the organisation (Mackie, 1993)
- Balanced Score Cards can be used to incorporate HCO (Health Care Organisation) strategy into the Patient Journey Modelling process. Only through the incorporation of strategic goals and measurements can organisational level quality improvements be realised (Curry et al. 2006)

Technology too, was part of the system, along with people, places and processes. Technology was discussed in terms of enabling the system to achieve its 'goals' or 'mission'

- Balanced Score Cards can be used to incorporate HCO (Health Care Organisation) strategy into the Patient Journey Modelling process. Only through the incorporation of strategic goals and measurements can organisational level quality improvements be realised (Curry et al. 2006)

Within the management discourse, technology was represented a superior tool that could replace the inefficient management practices and processes that contributed to the crisis in healthcare. This pointed to redesign of work practices. If technology was to replace inefficient practices, then it followed that the introduction of technical systems would necessitate change to these practices. While represented as the appropriate approach, work process redesign was acknowledged as a challenge:

- It is recognised that practice must be modified in order to obtain the most benefit from the system (Purcell, 1993)
- The current technological and information revolution has the potential to dramatically transform work organisations. The health care sector needs to work at clearly identifying, measuring, and where necessary, redesigning key care processes (Fitzpatrick, 1993)
- Sustained change through IT enabled initiatives remains a daunting task (McDonnell, 1999).
- Information technology is a major enabler of change (Cook, 2001)

Challenges to the potential success of technical solutions were located within other elements of the social system, particularly health professionals who were characterised as potentially reluctant to adopt new ways of doing things. Where the scholarly discourse sought to address this issue by fitting the technology into the health care environment, the solution for the management discourse

was for health professionals to adapt their work practices to technology. Technology was a tool for changing the system:

- Over the past twenty years, health information technology has improved substantially, yet the way people work and deliver care has barely changed over time (McDonnell, 1999)
- Measuring, and where necessary, redesigning key care processes to make the most appropriate use of systems and technology to support them. Changes in the behaviour of health care professionals are necessary in order to improve efficiency
- As organisations focus on the core business processes of delivering healthcare, they are having to reassess their business process to ensure that they are as effective and efficient as possible. IT will be used as a tool to assist with business process changes (McGill, 2001)

To disarm resistance, the discourse linked change with professionalism and resistance to change as unprofessional: ‘Constantly seeking improvement is a fundamental trait of professionalism’. It further defused resistance by invoking binary oppositions which contrasted the ‘new’, ‘modern’ systems with ‘old-fashioned’ ways.

The discourse therefore represented the primary role of information management systems as supporting effective system-wide management through provision of detailed operational data and statistical reporting. This focus on quantifiable data was emphasised through the consistent use of charts, graphs and statistical analyses. The emphasis on ‘the quantifiable’ highlighted one point of differentiation between the management and scholarly discourses. Where the scholarly discourse distinguished between information as appropriate for electronic manipulation, and knowledge development as a more complex, even esoteric human activity, the management discourse made no such distinction, speaking of data collection and manipulation to produce information. Knowledge and knowledge production were largely excluded from the discussion. Conference texts focused on describing projects and programs rather than on knowledge development practices and processes. These

discussions emphasised lessons learned from experience rather than insights gained from research. The emphasis on data and information was also evident in the representation of electronic data collection and analysis tools as the key to better management practice. While the discourse represented electronic systems as crucial to the future of health care, the focus was not on technical specifications and issues but on how information systems could be used to further the goals of management through effective information management.

- Central to the flow of information is the development of information systems to capture, process and output reports that can be used within the government bodies funding model (Green & Joyce, 2006)

Subject positions and status hierarchy

The discourse focused on the effective and efficient use of finite resources. It therefore privileged those responsible for the management of these resources, while locating the users of the resources in subordinate, albeit participatory positions. Higher status positions included directors, managers, executives, consultants, nurse-managers, and business analysts who determined the needs of the service. These statuses were constructed around of management positions and management expertise within health organisations. Therefore, within health informatics, those with knowledge of business and business practices were accorded a higher status. They were acknowledged as working in partnership with technologists and health professionals but were constructed as the senior partner. Health professionals occupied subordinate positions since they use information systems to deliver services, but need to be managed and accountable to ensure they use finite resources effectively and efficiently. This relationship represented a challenge to the power of clinicians and other health professionals. It was addressed by emphasising the lack of management expertise of clinicians who were constructed as focusing on clinical care. The discourse accorded technology professionals the status of the experts who produce and manage the information systems. At the same time, they were subordinate to the decision makers.

6.2.3 The Health Technology Discourse: IT is the answer

Focus

The health technology discourse constructed health informatics as primarily concerned with identifying and resolving the technical problems associated with the construction and implementation of technical information systems. This focus was established by statements linking technology concepts (computers, computer programs, information architectures, terminologies and standards) with clinical care concepts (clinical model, clinical notes, medical record, general practice, drugs and drug dosage) in such a way that technology was privileged. The titles of conference papers illustrate this linkage:

- Managing large databases of complex medical knowledge using conceptual graphs (Ellis, 1993)
- Application of classification and coding in a general practice computerised medical record system (Hall, 1993)
- Interoperability of Medical Information Systems using JAVA/CORBA with HL7 (Pradeep et al., 2001)
- The relationship between CEN13606, HL7 and openEHR (Schloeffel et al., 2006)
- Towards a repository for managing archetypes for electronic health records (Garde et al., 2006)
- Automatic conversion of clinical notes into SNOMED CT at point of care (Patrick & Budd, 2006)
- Automatic Mapping ICP2-PLUS terms into SNOMED CT terminologies (Patrick et al., 2006)

This focus was underpinned by an assumption of the superior capabilities of technology.

- The capacity of human brain is not infinite– computers have the potential to deal with increasing amounts of information (Wollersheim, 2001)

- Security issues need to be addressed – this must not rely on correct human behaviour (Patrick et al., 2006)

Issues for the discourse revolved around access and manipulation of data (e.g. data mining), interoperability and connectivity of technical systems (e.g. converting natural language to machine language through standardising language formats, modelling languages, conceptual schema languages), the adoption of standards and protocols, and security.

Themes and strategies

As with the scholarly discourse, the health technology discourse aligned itself with the empirical sciences and the associated positivist assumptions that developments in science and technology represent ongoing and objective progress. Technological determinism was evident in the health technology discourse where it manifested in an unquestioning acceptance of the superiority and inevitability of technology. Technology solutions were represented as superior and inevitable. Statements emphasised, both explicitly and implicitly, that technology was the most effective, efficient or even the only solution to the problems of health information management. Dualistic constructions represented technical systems as ‘state-of-the-art’, ‘industrial strength’, ‘innovative’, ‘efficient’ and ‘sophisticated’, while manual systems were ‘inaccurate’, ‘cumbersome’, ‘time-consuming’, ‘onerous’. Where disadvantages or shortcomings of technical systems were identified, these were presented as short term issues, inevitable challenges, even misunderstood advantages. These constructions were presented as self-evident truths.

The focus on technology enabled the discourse to exclude issues around power, politics and motives that guide and legitimate human actions. Thus, discussions around connectivity and interoperability focused on the technicalities around adoption of shared standards. Implications of adopting an interoperability standard which would enable linking with agencies such as the Federal Police,

the Australian Taxation Office, or Social Security, were excluded from the discourse. Where non-technical issues were addressed, they were often represented as impediments to the effective operation of the technical system. These impediments could be managed by informing, educating and persuading users of the benefits of the technology.

The health technology discourse used the data, information, knowledge conceptual continuum. The concepts were linked to electronic systems of different levels of complexity and sophistication. Databases were the repositories of data. Databases were the foundation of more sophisticated systems, such as electronic health records, which integrated data to produce information. The most sophisticated expert systems and decision support systems were concerned with knowledge management.

- Since the BPEL representation (model) is intended for machine execution, it should be complete and contain all implementation/technical details which are necessary for a workflow engine to understand and execute the representation (2008: 33:2)

While not an obvious aspirational goal of this discourse, the academic pursuit of knowledge was a recurring theme. Scientific research was conceptualised as offering truth, reason and the relevant facts to identify, explain and provide solutions to the problems of health information management. The discourse garnered support by linking with the international research community. Reference was made to ‘multi-national projects’, ‘world-wide interest’ and ‘compliance with international and national standards and guidelines’ for both research and technology projects.

- A number of groups around the world are independently working on natural language interfaces (Ellis, 1993)
- Through literature review and field study, this paper addressed a KM weakness in MGT labs with low-quality reports and rare knowledge capture (Gu et al., 2006)
- A design-science approach to modelling (Nugrahanto & Morrison, 2008)

By aligning itself with the dominant scientific discourse of modernity, the health technology discourse was very difficult to challenge. Challenging the discourse meant challenging the dominant discourse of modernity that science equals progress equals benefits. The discourse disarmed resistance through statements that appeared to acknowledge criticisms but reinforced the legitimacy of the health technology focus. This was achieved through use of terminology such as ‘contribution’ rather than ‘impact’ and by strategies that acknowledged clinical expertise but stressed the superior expertise of the technologist with regard to information management:

- Separation of dynamic and ever-changing clinical knowledge (archetypes) from rules and structure for data storage; (Leslie & Heard, 2006)
- Need for grass-roots clinicians to understand the role and practical application of archetypes. (Leslie & Heard, 2006)
- Communication with the average reader/grass roots clinician (Heard & Heard, 2006)

This further enabled the discourse to exclude consideration of many non-technical aspects of health information management. This was achieved by approaching information management from the perspective of ‘What is the best technology for achieving the desired outcome?’ This established the relevant issues as those specifically related to the internal structure and operation of computers and computer networks:

- A major goal in a modern health care system is to represent the state of a patient’s health and the health of a community in a way that is useful for automatic processing by computers (Ellis, 1993)
- We need models and prototype systems for seamless mapping of terms and concepts from one ontology to another (Cacayan et al., 2006)
- Transforming narrative prescribing workflows for machine execution (Nugrahanto & Morrison, 2008)
- Mapping between HL7 and openEHR to allow systems using different health standards to communicate with each other using translation services (Hansen et al., 2009)

This focus was emphasised through use of, and reference to, diagrams and pictorial representations in the form of computer modelling/programming, entity-relationship diagrams, conceptual graphs, and linear coding systems which ‘Turn clinical workflow descriptions into computer-coordinated service exchanges’ (Nugrahanto & Morrison 2008)

Subject positions and status hierarchy

The discourse privileged technical experts who talk to each other. The health informatics expert therefore was the possessor of technical knowledge. The discourse created boundaries through the extensive use of technical jargon and acronyms. This differentiated between those who had technical expertise and those who did not. Since those outside the discourse did not readily understand technical jargon, it acted as a tool to exclude outsider participation in discussion. This was reinforced by the simplification of jargon for the non-technical:

- The Conceptual Graph is a kind of knowledge representation language (Ellis, 1993)
- This paper offers a non-technical overview of an *openEHR* (Leslie & Heard, 2006)

Those with technical expertise therefore acquired the right to speak while ‘users’ occupied the subject position of the receiver of expert knowledge. Users were sometimes referred to as a seemingly homogenous group, but diversity within this group was also acknowledged, particularly in later conference papers, where users were differentiated as clinicians, health professionals, or patients. Health technology professionals spoke to each other about technology, rather than with, or about other professionals. When other professionals were mentioned, it was often within the broad category of ‘end-user’.

6.2.4 Populations discourse: Monitoring groups, not treating individuals

Focus

As with other discourses, the populations discourse constructed health informatics as concerned with managing health information to ensure effective and efficient health care services. Other discourses operationalised this as the effective use of health information for the treatment of individual patients in the immediate clinical environment and for the management of services to facilitate this treatment. For the populations discourse, however, the focus was not so much on individual patients, clinicians or organisations as it was on the collection, manipulation and analysis of large amounts of aggregated data for the primary purpose of monitoring populations to improve health rather than analysing individuals to repair problems. The populations discourse was therefore concerned with issues around the collection and use of aggregated data and information for service planning and implementation to proactively improve and maintain healthy populations. For this discourse, direct clinical care and individual health information were peripheral:

- Health information systems should be designed with a focus on improving the health status of the community (Neame, 93)
- In the context of the changing epidemiology of infections with epidemic potential, systems for the detection and monitoring of localised outbreaks as well as prevalence monitoring systems are required (Sintenchko, 2006)
- By using adequate data extraction tools, Divisions of General Practice can accurately map and analyse general practice clinical information in order to support the identification of service gaps (Besleaga, 2009)

The discourse established the focus of its activities by distinguishing between primary data and derived data. Primary data was comprehensive data about individuals generally collected and used in the immediate clinical or administrative setting. The purpose of primary data was treatment of the

patient. Derived data was created when the primary data from individual patients was collected and aggregated.

- Information from patient clinical records can be compiled into a database suitable for epidemiological research (Walker, 1993)
- Health providers: can plan for the provision of better health services based on the integrated analysis of health data (Hanson, 2006)

Derived data provided researchers and policy makers with the tools for understanding and improving the health status of groups and communities, and for managing the overall operation of health services and systems. The purpose of health informatics is to create the systems to turn primary data into derived data: 'informatics plays a role in "feeding forward" information gathered in one event or one encounter' (Neame, 1993, p. 282)..

The discourse established an instrumental, rational, orientation by the representing all aspects of health care as able to be objectively measured and analysed. This was operationalised by an emphasis on objective data collection and analyses which would be used for decision making that was 'not influenced by politics or persuasion':

- Inefficiencies in public health monitoring and information management will be allayed by effective and efficient collation and analysis of surveillance data (Sintchenko, 2006)
- Ability to make comparisons; accountability; rationalised approach (Greville, 1993)

This focus was justified by the claim that collection and analysis of aggregated data delivers benefits that will flow throughout the health system and society in general:

- Uniform national information provides the only reliable basis for realising the benefits that will flow to all levels of the health care system, including the States and local communities, patients, care providers, managers and planners...Uniform national statistics assist identification of major national health trends and broader epidemiological studies (Greville, 1993)

- Australia has a rich repository of health and community data repositories that could potentially be linked to help find answers to important health and social questions (Hansen, 2006)
- Health information is concerned with the health of individuals, populations, provision of health services, their cost, use and outcome (Greville, 1993)

Themes and strategies

A number of interrelated practices operated to confine activity in the discourse within these parameters. These included adopting a rational, objective orientation, constructing health environments as systems, differentiating between data, information and knowledge and establishing the role of technical systems. This enabled the discourse to exclude social issues around the implementation of information systems in the health care environment. Patient management, work roles, change management and other social and organisational issues were not within the parameters of the populations discourse.

The rational, objective orientation of the discourse was reflected in statements that referred primarily to data collection and information production as objective pursuits while ignoring the potentially messy concepts of knowledge and knowledge production. This construction supported the management discourse but contrasted with the scholarly and clinical discourses where knowledge is not produced by technical systems, but is a human function. Within the populations discourse, data and information supported informed decision-making:

- Information is being increasingly recognised as a necessary prerequisite for well managed healthcare (Greville, 1993)

The discourse used binary oppositions to justify its focus. Decision-making based on the analysis of aggregated data drawn from the various data sets, data warehouses and population registries was described as ‘reliable’, ‘valid’ and

‘providing a solid basis for planning and policy making’. This contrasted with less positive references to ‘subjective’ decision making:

- We recognise the advantages of adopting a rationalised approach to information development, rather than a piecemeal approach. Until now questions have been resolved on an ad hoc basis. This ad hoc approach has generally been costly and inefficient (Greville, 1993)
- This analysis introduces the advancement of formalisation and objectivity into the once rather subjective area of prediction (Lin, 2006)

The discourse established its focus by referring to ‘large-scale data collection’, ‘data sets’ and ‘aggregated data’ for creating ‘population-based registries’ and ‘national health information repositories’. The goal of this activity was to support public health planning, population health, epidemiological studies and medical research. Within these parameters, appropriate concerns for health informatics were technical issues related to the development and implementation of systems capable of accessing, manipulating and disseminating large amounts of data and information. Issues within the scope of the discourse included interoperability of systems, standards, data structures and data quality, but also data protection and privacy issues associated with surveillance of populations and expanded access to personal information. The populations discourse therefore emphasised technology as an integral element of health informatics. Recurring statements highlighted the way technology enhanced data management capabilities while emphasising the need for continuing advances in technical systems:

- The growth of information technology has seen a substantial increase in our capacity to collate, manipulate, analyse and move information (Greville, 1993)

Primary concerns for the discourse were identified as technical issues related to ensuring data access and data quality. Data access issues focused on creating systems that enabled access to the primary data that resided in widely dispersed and disparate health information systems. These were often defined in terms of interoperability and standardisation:

- This includes uniform approaches, common data sources, better linkages across complimentary systems (Sintenchko et al., 2006)
- A common requirement of applications in public health and biomedical research is the ability to link records in disparate databases. This is particularly the case in Australia's health system where data about a patient is spread between many custodians (Pang & Hansen, 2006)
- The first priority is to improve data collections available. An important strategy is the setting of national data definitions and standards (Greville, 1993)
- The health data environment consists of disparate data held in many different databases. Accessing this data can be difficult for technical or security reasons (Hansen, 2006)

Data quality issues included the need to ensure completeness of data sets, data purification, redundancy and integrity:

- Quality data is essential for effectiveness as it is the key for needs assessment, service planning, integrated care planning, disease management, delivery of care and evaluation of delivery and outcomes (Soar and Croll, 2001)

While these issues were similar to those identified in other health informatics discourses, particularly the health technology discourse, the population discourse differentiated itself by claiming that the effective and efficient use of derived data required special techniques of data collection and interpretation. Discussions spoke of 'statistical algorithms', 'data warehousing' 'data mining' and issues related to building and managing 'very large databases'.

- Data mining is a set of computational methods that use statistics, probability theory and a variety of artificial intelligence methods, including machine learning and pattern recognition (Lin, 2006)

The discourse defused resistance by pointing to growing interest and informed support from clinicians, policy makers, planners and managers. This was contrasted with the claim that it was a lack of understanding that was the barrier

to adopting the information management practices offered by emerging systems:

- The Australian Health Ministers Advisory Committee endorsed the National Health Information Agreement between the Commonwealth, State and Territory health Authorities, the Australian Bureau of Statistics and the Australian Institute of Health and Welfare (Greville, 1993)
- The establishment in January 2000 of the Australian Council for Safety and Quality in Health Care reflects the growing national focus on quality. One of the key aims of the Council's action plan is better use of data to identify, learn from and prevent systems failures (Innes, Roberts, Rust, 2001)
- Many health professionals still practice much of their working life without much on-going contact with the growth of information, knowledge and techniques (Neame, 1993)

The discourse utilised the concept 'systems' to further delineate the scope of activity. The complexities of health care and health data were represented as issues that could only be effectively understood by viewing people, processes and structures as interconnected elements in a system:

- It is necessary to take a holistic view of the system in order to understand and improve its performance. The primary purpose of this system is to improve the health status of the population (Neame, 1993).
- Benefits will result from a better understanding of the elements of the system and how they interact; (Greville, 1999)

Conceptualising health care as a system established the appropriate scope for the discourse as 'the environment'. This justified the span of activity as incorporating the whole spectrum of people, processes and structures in health care. In applying the concept to the wider society, the discourse was able to justify broadening relevant data from health data to the collection of a range of social, behavioural and environmental data. Individuals were represented as operating within wider social systems, the elements of which interact to affect

their health. The activities of the discourse were therefore directed towards understanding the dynamics of different elements of the system with a view to minimising ill health and maximising service delivery where it was needed:

- The practice was able to geographically map the incidence and prevalence of mental illness in the local government area in order to support the identification of service gaps and hence the planning of mental health services for the community (Basleagea, Neill & Kelly, 2009)

Subject positions and status hierarchy

Within the populations discourse, subject positions were based on knowledge-related research and expertise relating to manipulation and interpretation of large data repositories. These drew on the established status positions of public health, rather than within the discipline of health informatics. Higher status was accorded to academics, particularly researchers and epidemiologists.

6.2.5 The clinical informatics discourse: The patient at the centre

Focus

The clinical informatics discourse used the language of biomedicine to establish the focus for health informatics as the activities of clinicians rather than those of managers or other non-clinical professionals. The area of interest for health informatics was therefore delineated as the immediate clinical environment. This established a narrower focus than the scholarly, management or health technology discourses which represented health informatics as spanning organisation-wide activities and systems. These parameters were established by consistent use of terms such as ‘clinical’ and ‘medical’ to qualify information management and information systems. The uniqueness of the clinical environment was emphasised both in terms of the complexity of medicine and medical care and also in cultural terms where reference was made to established professional relationships and medical traditions: ‘Medicine has always been practised in a structured environment with strong traditions’ (Hage, 1999).

Binary oppositions highlighted the unique clinical environment, which required sophisticated clinical information systems, with the simpler, more straightforward systems requirements of health administration and management environments. Aspirational goals were conceptualised in terms of the capacity for information systems to support doctors to more effectively perform a wide range of clinical activities to benefit patients. The role of technical systems was to deliver information in a reliable, accurate and timely manner to enable clinicians to provide this treatment and care:

- Faster, more efficient access to data to assist in diagnosis, treatment, monitoring (Van der Weegan, 1993)
- Computerised test management systems which allow doctors to place orders for tests and view test results electronically can assist in this process (Callen et al., 2008)

Achievement of goals was constructed in terms of the ‘effective’ and ‘efficient’ provision of information, ‘improved treatment processes’ and ‘patient outcomes’, and ‘clinician uptake and satisfaction’. Clinical diagnostic systems, clinical decision support systems and electronic medical records systems were represented as the tools to achieve these goals and outcomes. This linked technology with the clinical environment but reversed the relationship explicated in the medical informatics discourse, allocating technology a subordinate position and privileging medical knowledge.

Themes

The aspirational goals of the discourse were incorporated into a strong theme of information systems as socio-technical systems. Socio-technical was understood as focusing on the interaction between the technical system and the social environment into which it was being introduced. The discourse explicitly emphasised the need to look beyond the internal structure of computer programs to explore the interaction between the system and the clinical environment:

- The socio-technical view attempts to understand the contribution of phenomena at the human social level to the performance of technical systems. Socio-technical systems analysis has provided us with a powerful framework with which to analyse the reasons behind the poor acceptability, uptake and performance of many information and communication technology (ICT) interventions (Coiera, 2006)

The theme constructed specific issues for health informatics in terms of the design and implementation of clinical information systems in the complex clinical care environment. It emphasised the need to understand the culture, clinical practices, workflows and dynamic nature of medical practice within this environment. It also emphasised the importance of ensuring that the introduction of information systems resulted in minimal disruption to the activities of clinicians:

- First define what doctors do then suggest how *appropriate* solutions can streamline healthcare delivery (Hage, 1999)
- It is important to explore how (system) is integrated into clinical work practices in different clinical environments....lack of communication between medical error strategists, information technologists and medical staff at the coalface is a major barrier (Callen et al, 2006)
- This technology is appealing to medical staff as it aligns with their normal workflow (Brophy et al., 2006)
- Matching the clinician's workflow with appropriate technology (Brophy et al., 2006)
- The system failed to fully adapt to the context and work practices of the site (Li et al., 2009)

Terms such as 'usability' and 'user friendly' emphasised that clinicians should have significant input into the development and implementation of technical systems to ensure that the systems supported and enhanced clinical practice:

- Systems fail because they don't deliver what the clinician- needs; need to understand specific information needs of medical practitioners and the nature of decision making under uncertainty (Sintchenko, 2001)

- The driving force of those systems were clinicians and the main purpose was to support clinical practice (Jayasuriya: 1993)
- The user must remain in control of interactions (passive presentation is preferable to ‘pop-ups – many GPs turn these off) – speed, simplicity and unobtrusiveness were emphasised by the group (Calabretto, Lewis & Reeve, 2009)
- Many features were rejected because they complicated the interface or were ‘programmer’ functions rather than ‘doctor’ functions (Parle & Lassere, 2008)

While the clinical informatics discourse acknowledged the potential benefits of technology for professional clinical practice, the socio-technical focus enabled it to challenge the technological determinism evident in some other discourses. Thus, clinical informatics discourse did not unconditionally support the introduction of technology. Technology must prove its worth:

- They do not see that using such a system would be better than what they have in their manual systems (Cacek, 1993)
- Clinicians require an appreciation of the limitations of current video conferencing, they need to take account of these limitations (Cooper, et al. 1999)
- Clinicians are motivated by evidence (Rushton et al., 2008)

The clinician must also guard against the imposition or negative impact of information technology, to ensure that technology did not control the clinician but remained a tool. Statements, including titles of conference papers, reflected this perspective:

- IT- the servant of the physician (Scott & de Jersey, 1999)
- Computer based “expert assistance” for radiologists (Wilson et al., 1999)
- Can Australian GPs trust their software? (Boyle et al., 2006)

The discourses stressed that technology should support and enhance clinical practice, and meet the needs of the health professional rather than seeking to redesign work flows and work practices. The discourse therefore adopted a

position with regard to the role of technology that was in direct opposition to the health technology and managerial discourses. Technology was relegated to a supporting role of enhancing clinical practice and meeting the needs of the health professional rather than forcing a redesign of work flows and work practices.

Subject positions and status hierarchy

The subject positions and status hierarchy within the clinical discourse pointed to its links with the discipline of medicine. The discourse implicitly accepted the traditional biomedical hierarchy of subject positions identifying potential conflict around the introduction of information systems at many levels:

- There are already significant conflicts between administrators and medical practitioners (Chien, 2006)
- There is a contest between clinicians and those involved in administrative tasks for funding for resources (Bennett)
- Junior doctors...felt powerless to voice or change the system...many initiatives were seen as micromanagement of the administrators...there were instances of misuse of incident reporting as a threat to win personal arguments (Chien, 2006)

The discourse distinguished between the technology expert and the knowledge expert. Clinicians, as knowledge experts, were constructed as having the authority to drive the development of clinical systems. They were also represented as having the authority to reject systems they consider not useful or appropriate:

- Clinicians were positive towards CPOE in terms of efficiencies but not in terms of improvements in patient care (Callen et al., 2006)
- Doctors are unwilling to buy a system because they do not see that using such a system would be better than what they have in their manual systems (Bennett, 1993)

- If clinicians are not convinced that the system can offer clinical value or improve patient outcomes then this may be a key barrier to successful uptake (Callen et al, 2006)

Systems developers, the technical experts, were subordinate and needed to consult with clinicians who were both content experts and end-users of the systems:

- Black-box-ology – emerging *medical specialty* of implementing *relevant* IT solutions, focusing on the benefit gained by the end user and leaving the *computer nerds* to deal with the technology (Hage, 1999, emphasis in original)
- There needs to be collaborative research efforts between the people developing systems and those with the skills to measure the system's clinical impact (Bennett, 1993)
- Historically, information systems have been rejected because they have been designed somewhere external to the socio-technical system (Coiera, 2006)

Patients were represented as in partnership with clinicians, but they were the junior partner:

- Self-management needs to be guided to be effective and to guard against patients being misinformed (Ganguly et al., 2001)

In later texts there were indications of colonisation of the clinical informatics discourse by the management discourse. The consumer appeared alongside the patient, and management themes of business processes, efficiency, cost-savings and cost-effectiveness were introduced into the discourse.

The clinical informatics discourse prioritised clinical practice and clinical knowledge, emphasising the role of health informatics in supporting these activities. It did not explore political aspects around power and influence shaping the use of personal information, or the implications of various uses for the development of health informatics applications.

6.2.6 Nursing informatics Discourse: A distinct area of expertise

Focus

The sixth discourse identified in the study was the nursing informatics discourse. Nursing informatics differentiated itself from other discourses by its focus on the field of nursing. The discourse emphasised that nursing practice was not separate from the overall practice of health care, ‘in reality we cannot set nursing apart and regard it as a separate entity from health care’ (Foster and Conrick, 1993, p.142). At the same time, it stressed that nursing informatics and nursing practice were distinct areas of expertise.

- Nursing informatics is a unique body of knowledge which integrates information technology/information sciences with the science and *art* of nursing (Thoms and Chu:99:48)

The nursing informatics discourse addressed information management and information technology issues primarily in the context of nursing practice, nursing administration, nursing research and nurse education. This allowed it to emphasise and reinforce that nursing practice was different, and that information systems should focus on meeting the specific needs of nursing.

- Nursing practice is more expansive than these quantitative measures of work efficiency (Axford, 1993)
- The focus of nursing deliberations was on the enhancement of patient care; clinical and management information would be directly related to monitoring patient outcomes, staff requirements and costs (Walker & Ford, 1993)
- This model seeks to ensure that Nursing’s information technology is indeed linked to Nursing’s business goals and objectives, is in alignment with the Corporate goals and objectives and complimentary to the Corporate IT strategy (Leeder, 1993)
- Nursing classification systems and nursing data sets are critical to support the processes of nursing and advance the knowledge necessary for quality cost effective, equitable healthcare (Foster & Conrick, 1993)

Themes and strategies

The discourse established parameters by referring specifically to nursing knowledge and practice, and by differentiating these from non-nursing duties and practices. Common terms from other discourses were preceded with the term 'nursing'. Thus, the discourse spoke of nursing care, nursing information systems, nursing data, nursing budgets, and nursing workflows. This excluded discussion of non-nursing health informatics issues.

- Decision support in a nursing context is different to that normally found in, for example, provision of clinical guidelines (Ahamed, 2006)
- Nursing informatics is a unique body of knowledge (Chu & Thom, 1993)
- Nursing data is unique within the health system (Foster & Conrick, 1993)

Nursing was constructed as information intensive. 'Nursing as a discipline has been concerned with data since the early days of Nightingale' (Gogler et al 2008). This enabled the discourse to justify nursing informatics as a distinct knowledge domain, differentiated from other areas within the informatics and health professional domain. In doing so, it established a mutually reinforcing relationship between the nursing and nursing informatics. The unique nature of nursing practice justified the need for a unique body of nursing informatics knowledge, while the development and application of nursing informatics contributed to nursing knowledge and in doing so, enhanced understanding and thus the status and influence of the nursing discipline.

- A unified nursing language will assist the nursing profession to communicate more effectively with each other and to convey to others what it is that nurses do (Shannon and Hovenga, 99: 168).
- The introduction of a NMDS and standardised nursing data, arguably the greatest barrier hindering nursing research on a national and international basis, would be removed. It is critical that these developments are undertaken quickly and efficiently and that the chance for professional unity is not lost. If this is lost nursing will lose the chance to play an integral role in developing quality, cost effective and equitable health care (Foster and Conrick:93:143)

As with other discourses, the nursing informatics discourse used the concepts data, information and knowledge. In doing so, it differentiated between data and information on the one hand, and knowledge, on the other. Data and information were used when the focus of discussion was on implementing information technology to support nursing practice. Information technology was the means for manipulating data and information. Knowledge was referred to in the context of academic knowledge development. To emphasise its status as a distinct knowledge domain, the nursing discourse employed the processes of academic knowledge production, speaking of 'qualitative', 'quantitative' and 'mixed methods' approaches to research, 'meeting the academic strictures' around ethics and informed consent, and presenting research findings in academically structured formats.

As with all discourses, technology was represented as an increasingly integral element of health care and health information management, but in the nursing informatics discourse, technology was constructed as a tool, with an enabling, facilitative role rather than as a central focus of nursing informatics activity:

- The health care industry will become increasingly reliant on information technologies (Thom & Chu, 1999)
- Computers are inevitable in health care (Ho & Hovenga, 1999)
- We must demand that technology be used to create tools that support our performance rather than obscuring it (Thom & Chu, 1993)

This representation of technology was underpinned by claims about the complex nature of nursing and therefore of nursing data and information. The discourse used terms such as 'high-touch' and 'high-tech' to establish a dualism between the professional practice of nursing and the use of technology in the nursing environment. Professional practice was represented as occurring at an intimate level of human interaction, while technology was represented as non-caring machines. The discourse stressed the importance of ensuring that high-

tech systems did not interfere or undermine the high-touch role of nurses as carers:

- The impact of information technology on nursing itself, a professional practice which occurs at an intimate level of human interaction, requires attention (Axford, 1993)
- Much of the work they were told to perform were non-nursing related duties which increased their workload (Ho & Hovenga, 1999)
- Nursing is high touch – compared with high tech (Chu & Thom, 1993)

The discourse represented nursing as having an ambivalent relationship with technology. While acknowledging the possibilities, nurses are uncertain and apprehensive about incorporating technology into their practice: ‘Nursing is trying to define its relationship with technology’. The attitude of nurses towards technology was constructed in negative terms of non-compliance, passive resistance, or sabotage. These attitudes were attributed to ignorance rather than lack of knowledge and the means for addressing these attitudes was education of nurses by nurses:

- While nurses are incompetent, they are not, in principle opposed to information management. They just need to be informed and supported (Chu & Thom, 1993)
- Attitudes to computers could be positively changed by attending a computer literacy course that emphasised the responsibilities and the functional relativity of computers to nursing (Moralee et al., 1993)
- There is a gap between the knowledge that nurses have and that which is required to take full advantage of the technology (Axford, 1993)
- Respondents suggested adequate training prior to computerisation implementation (Ho & Hovenga, 1999)

The discourse employed metaphors that spoke of conflict: ‘Ground Zero: The point at which information technology is introduced into clinical nursing practice, challenging and replacing standard practices, has the potential to be an explosive situation’ (Bartley, 1993), while education was spoken of as a

powerful weapon in the fight to erase the misunderstandings about nurses and nursing practice.

A concern for the nursing informatics discourse was to promote the discipline of nursing. A recurring theme emphasised that the uniqueness of nursing and nursing informatics was largely unrecognised. To support this claim it pointed to instances where the nursing perspective had been largely overlooked, or omitted from health informatics initiatives:

- The development of the Australian Health Minimum Data Set, true to early development in other countries, contains no nursing data. Once more the omission was repeated! (Foster & Conrick, 1993)

This was represented as part of a long-standing lack of appreciation and understanding of the profession of nursing itself. Terms such as 'doctor's handmaiden' were used to illustrate the way nurses and their work have been negatively characterised. Nursing informatics was represented as a means for addressing the misconceptions and for informing the health community about the contribution of nursing care:

- Standard documents will also go some way to facilitate the definition of the scope of nursing practice (Conrick, Fraser, Hullin, 2001)
- Technology can provide the information to challenge the notion that 'nursing is still buried among the brooms, breakfast and the building mortgage' (Plummer, 2006)
- There is a need for unified nursing language to assist profession to communicate more effectively with each other and to convey to others what it is that nurses do (Shannon & Hovenga, 1993)
- The system resulted in changes in professional roles, with a reduction of the 'doctor's handmaiden' tasks – it challenges traditional roles (Bartley, 1993)

The concern with the status of nursing and nursing informatics was a strong aspirational theme expressed in adversarial terms through the use of metaphors such as 'weapon', 'battle', 'explosive situation', 'potential violent situation',

and ‘sabotage’. The recognition of nursing informatics as a distinct knowledge domain was thus constructed as a conflictual rather than a cooperative enterprise.

Subject positions and status hierarchy

The concern to differentiate nursing informatics from other informatics professionals was reflected in the status positions within the nursing informatics discourse. These were structured in the context of the nursing profession. The discourse privileged the nurse as the nursing informatics expert. The discourse differentiated between those with nursing informatics expertise and those without. The former were accorded the authority to speak.

6.3 Discussion

The analysis showed that between 1993 and 2009 the academic discipline of health informatics was shaped by six discourses. Common across all six discourses was the construction of health informatics as concerned with the collection, storage, manipulation and dissemination of health information. Since health informatics emerged as a possible means for managing the ever-increasing amount of information being generated in the delivery of health care, this broad shared vision was to be expected. The discourses were differentiated according to the scope, focus and issues they delineated as being within the parameters of this shared vision.

The scholarly discourse focused on establishing health informatics as an academic discipline, emphasising the adoption of academic research and teaching regimes. The discourse spoke of a need for standardised skill-sets, common knowledge and a united approach to education and training. Horsfield & Peterson (2000) identified a similar discourse, the pedagogic discourse, in their study. While the pedagogic discourse did not overtly advocate the adoption of academic knowledge production it was concerned with ensuring

clarity and a common purpose in education and scholarly debate through 'consolidating and stabilising E-Health course content and by seeking strong links with industry' (2000, p. 7). Horsfield and Peterson identified an emphasis on uniformity of terminology which, they suggested 'ignored or obliterated differences, disputes and dissension in the field' (2000, p. 7). Similarly, in this study, the emphasis in the scholarly discourse on a cohesive, unified discipline served to challenge an emerging critical discourse by marginalising or negating views that challenged the united approach to core knowledge.

The health technology discourse constructed health informatics as primarily concerned with developing the best technological solutions for managing personal health information. Horsfield and Peterson also identified a technology discourse which they referred to as the 'discourse of information technology (IT) as progress' to indicate its association with the 'ubiquity and plausibility of the discourse of technological determinism' (2000, p. 9). Technological determinism was also a theme in the health technology discourse in this study. It manifested in an unquestioning acceptance of the superiority and inevitability of technology. Conference texts focused on technology issues and solutions, while excluding many non-technical aspects of health information management. The health technology discourse successfully colonised other health informatics discourses. This was evident in the way these discourses increasingly privileged health technology issues and solutions. This was very evident in the special edition of the *electronic Journal of Health Informatics*, where issues of privacy were constructed in terms of technology rather than human solutions. Previously privacy and security had been linked but differentiated with privacy considered to be a human issue and security a technology issue.

Horsfield & Peterson identified a strong commerce theme within their e-health as commerce discourse (2009, p. 9). Although a strong association with commerce was not identified in the management discourse in this study, there

were synergies between the two discourses in their focus on such issues as business processes, financial issues, efficiencies and quantifiable performance outcomes. The management discourse represented health informatics primarily as a management tool to be used for activities ranging from effective and efficient policy, planning and evaluation, to supporting governance and accountability systems for health professionals, to clinical care planning. This discourse was more concerned with the application of health information systems than with academic issues around knowledge production. It challenged the health technology discourse which privileged technology, the scholarly discourse which privileged academic knowledge production and the nursing informatics and clinical informatics discourses which constructed health informatics issues in terms of patient care.

Horsfield and Peterson identified a medical practitioner discourse which encompassed 'medical practitioners and hands on health workers' (2000, p. 8). This study differentiated between medical practitioners, finding clear differences between the clinical informatics and the nursing informatics discourses. These focused on the operation and contribution of health informatics in the professional practice of medicine and nursing respectively. The clinical informatics discourse prioritised clinical practice and clinical knowledge, emphasising the role of health informatics in supporting these activities. The nursing informatics discourse constructed nursing informatics as a distinct area of expertise within the broader health informatics discipline. The discourse privileged the nurse as the nursing informatics expert. In later texts there was evidence that the clinical informatics and nursing informatics discourses were subject to colonisation by the management and health technology discourses.

Two discourses identified in the Horsfield and Peterson study were not found in this study. These were the consumer discourse and the critical discourse (2000,

p. 6). Horsfield and Peterson locate these discourses low in their hierarchy, indicating their limited influence on telehealth diffusion. In this study the consumer appeared as a subject position, primarily in the management discourse rather than as a discourse in its own right. Other discourses used alternative constructs for this status. These included 'patient' in the clinical informatics and nursing informatics discourses and 'user' in the health technology discourse. While a number of statements in various texts pointed to critical opinions expressed by some individuals in diverse locations, this analysis identified no critical discourse, or even critical theme. The consistent and emphatic linking by all discourses, of expanding information use with positive outcomes, together with the aspirational goal for acceptance as a distinct area of expertise may well have operated to suppress a critical discourse. While the limitations of generalising from one discourse analysis to another are acknowledged, it is also noted that the findings from these two studies point to the dominance of some discourses across the health informatics community.

6.4 Conclusion

This chapter challenged the traditional historical narrative that represents the health informatics discipline as an evolving cumulative body of knowledge. An analysis of texts from within the discipline identified diverse views. While these are represented in historical narratives as characteristic of an emerging discipline, this study adopted the view that this diversity represented competing discourses seeking to impose a particular understanding of health informatics on the community. The analysis showed that between 1993 and 2009 the academic discipline of health informatics was shaped by six discourses. At the same time, while discourses were clearly identifiable, the academic discipline of health informatics was not neatly divided into camps or communities supporting particular discourses. Over the sixteen year period covered by the study the texts pointed to discourses interacting, competing, cooperating and

colonising each other as they sought to control the academic discipline. While a particular discourse may have dominated at a particular period, no discourse dominated to the exclusion of all other discourses.

The analysis of conference texts provides only part of the picture. Discourses do not just occur in written texts. They also comprise social relations and practices. More successful health informatics discourses compete to institutionalise social relations and practices which enable them to control knowledge production and dissemination within the discipline: 'the view that will ultimately prevail is a political question of funding, institutional arrangements and the like. They are not a discipline because they got it right, but because they have convinced enough people, and aligned themselves with enough people that matter' (Introna, 2003, p. 236). The study therefore sought to identify the institutional processes and relations implemented by more successful discourses. The next chapter describes the institutional processes and relations identified in the study.

Chapter 7: Institutional supports and processes

7.1 Introduction

This chapter addresses the second question posed by the study: *What is the relative influence of the health informatics discourses identified within the academic discipline?* Discourse is not simply reducible to, or the same as, linguistic patterns or language use. Foucault points out that the power in language links to, and stems from, material and tactical forms of power. Successful discourses therefore establish networks of institutional processes and relations that control the production, dissemination and application of disciplinary knowledge. Therefore, when Musen & van Bommel (2003) point to the indicators of a successful health informatics discipline, they are also pointing to evidence of successful discourses within the discipline.

Chapter Six summarised the historical narrative of health informatics as an academic discipline. It also described health informatics discourses, which from a Foucauldian perspective competed to shape the discipline. This chapter links these two elements by mapping the development of the discipline between 1993 and 2009, while also identifying the influence of the discourses at each period when texts from the HISA Conference proceedings were analysed. Since the struggle to control disciplinary knowledge occurs in both written texts and in the social relations and practices generated by the discourses this chapter focuses on the social relations and practices generated by more successful discourses. It draws on the concept of discourse communities to explore the emergence and coalition of these relations and practices.

This phase of the study focussed on describing the institutional processes and relations which enabled the more dominant health informatics discourse

communities to actively maintain, replicate and expand the knowledge, social practices and social relations of more successful discourses while marginalising others. It analysed conference texts but also drew on additional texts such as official documentation from government, academic and other institutions, professional organisations, journals and other publications.

As with many aspects of Foucauldian influenced analyses, there was no clear indication, either in his work, or in the secondary literature, about which institutional processes and relations Foucault considered significant. In Chapter 3, the indicators used to identify the existence of discourse communities were delineated as:

- Institutionalised processes supporting the production and dissemination of disciplinary knowledge and practice
- Mechanisms to control the production of health informatics skills and knowledge
- Mechanisms to accredit an identifiable system of status positions acknowledging health informatics expertise
- Organisations that promote the discipline and profession
- Mechanisms for dissemination of approved knowledge
- An identifiable active community of interest

The analysis did not approach the development of health informatics as an evolutionary process. It adopted Roth's suggestion that 'a history *of* the present means writing a history *in* the present,' (1981, p. 43). Each of the three periods analysed represents 'a diagnostic of the situation at that particular point in time' (Roth, 1982, p. 43). Identified changes and continuities between periods are interpreted as the outcome of struggles between the discourses within the discipline. This emphasises the Foucauldian understanding of knowledge development as 'always formed in the confluence of encounters and chances, during the course of a precarious and fragile history' (Foucault, 1988c, p. 37).

To identify the relationships between discourses within the conference texts, the analysis looked for

- The number of individual papers in which a discourse dominated: multiple discourses may occur within any text. However, parameters around conference papers, such as required format and word length, resulted in the majority of papers being largely being dominated by one discourse.
- The ‘reach’ of the discourse: for example, the ability of a discourse to shape the structure of conference papers.
- Evidence of alliances, collusion or colonisation: such as the appearance of concepts from one discourse in other discourses: for example, the appearance of management concepts and themes across a number of discourses may point to either colonisation or alliances occurring within the field.

Institutional structures and processes that supported particular discourses for each of the three periods, as described in Chapter 3, were identified by mapping:

- Academic faculties, departments and schools from which papers/authors originated: consistency, growth and the emergence of sites designated as being concerned with health informatics were noted.
- Enunciative modalities: continuities and change across the three periods of the study, particularly moves from reference disciplines to health informatics.
- Institutional structures and processes that governed the activities of the discipline and the profession.

7.1.2 Discourse Communities

Discourses originate in localised communities, in dispersed institutions as groups of people who share a particular understanding about health informatics

begin to interact. It is through common experiences and the undertaking of shared discursive action, that discourse coalitions arise. Discourse coalitions are communities of individuals who share speech, thought and understanding about issues (Hajer, 2003; Skillington, 1997; Torgerson, 2003). It is within these communities, rather than as a result of individual actions, that discourses emerge:

Instead of meaning-making as something that is done by minds, I prefer to talk about it as a social practice in a community. In this sense, we speak of a community, not as a collection of interacting individuals but as a system of interdependent social practices: a system of doings, rather than a system of doers (Lemke, 1995, p. 8).

As discourses within each community expand, they come into contact with other discourses, with some becoming more influential than others. Knowledges which remain on the margins become 'subjugated, disqualified as inadequate to their task or insufficiently elaborated: naive knowledges, located low down on the hierarchy' (Foucault, 1980, p. 82) while more influential discourses coalesce and integrate. In doing so, they are able to garner the institutional backing, resources and training necessary for them to actively maintain, replicate and expand the knowledge, social practices and status relationships that constitute the discourse of which they are part. Institutional support is 'a political means of maintaining or of modifying the appropriation of discourse with the knowledge and power it carries with it' (Foucault, 1972, p. 219).

7.2 Shaping the academic discipline

The following discussion maps the institutional processes and relations of the discipline of health informatics for the period of each text analysis. In doing so, it considers the relative power of the discourses in generating and shaping these relations and practices

7.2.1 1993: Emerging interest in the field

At the time of the inaugural 1993 conference, while there was clearly interest in the field, there was little evidence of localised communities with the location of authors suggesting that interest in health informatics was generated primarily from within other professional, academic or commercial groups rather than from within identifiable health informatics communities. As shown in Table 7.1, the fifty-three conference papers originated from widely dispersed academic institutions, public and private sector health service organisations and commercial sites across all Australian states. These included diverse schools and faculties in twelve different universities, a wide range of divisions, departments and facilities within five state health services and three private healthcare organisations and six unrelated commercial sites.

Table 7.1 Location of authors, 1993

Academic Institution	Faculty/school/division
Australian Institute of Health and Welfare (Canberra)	Health Services Div Health technology division
ACHS	ACHS evaluation program
University of Queensland	Dep't computer Science Dep't surgery Brisb Medical School (social & preventative med)
University of Central Queensland	Faculty of Health Science
QUT	<i>Law Faculty</i> <i>Nursing</i>
University of Wollongong	Public Health and Nutrition
University of Sydney	Health information management
UNSW	Not included
University of Melbourne	Department of Technology Services
Deakin University	School of Nursing
La Trobe	Department of Nursing
University of Adelaide	n/a Information Services, Barr-Smith library
University of SA	Communication and Information studies
Health service institution	Department/division
Australian council on health care standards Community nursing information data set	
Queensland Health	McKay Base Hospital Greenslopes Repatriation Hospital Brisbane
NSW Health	Management Division Information management Division

	Area health service St Vincent's hospital
Vic Health	HACS child and family health program Geelong hospital Alfred Hospital Monash medical Centre Extended care sector
SA Health	Women's and Children's Hospital
SA Health Commission	Nursing Branch
WA Health	Royal Perth Hospital
Private practitioners	Victoria (GP) NSW (Clinical consultant)
Business/commercial site	
Health Informatics Consulting	NSW
<i>Fleming associates</i>	NSW
Benero Services	NSW
Deloitte Touche Tohmatsu	Management consulting services, Victoria
Nursing and Healthcare Information Systems	N/A

The majority of these sites contributed only one paper and more than half of the papers were written by individual authors. Of the co-authored papers, less than one quarter were the result of collaborations across institutions. While there appeared to be a concentration of papers within some institutions (4 from the University of Adelaide, 4 from the University of Queensland and 4 from the University of Central Queensland), a closer analysis revealed that these were either written primarily by one author, or were spread across several Faculties or schools within the institution. Three of the four papers from the University of Adelaide were from the same author, while at the University of Central Queensland, one author again contributed to three of the four papers submitted (Appendix 1). This pointed to authors working relatively independently of one another, rather than to groups interacting within a community of interest. Diverse professional and/or disciplinary environments reinforced this view. The terms *e-health* and *health informatics* were used to designate one health service site (Medical Informatics Unit within the Monash Medical Centre) and one commercial site (Health Informatics Consulting). All other sites had other disciplinary or professional affiliations. Health informatics was an area of interest within other professions or disciplines rather than distinct field in its

own right. The Health Informatics Society of Australia, established in 1992, reflected this view of health informatics as comprising diverse groups. In its documentation, HISA referred to various groups interested in health informatics but did not describe these groups as comprising a health informatics community or discipline: 'The HISA constitution provides the ability for individuals and organisations who share a special and common interest in health informatics to form a group' (Parker, 1993). HISA's view of its own role was 'largely one of communication between the various informatics groups in Australia' (*Informatics in Healthcare Australia*, November 1993). This view was also evident in statements from conference texts that emphasised the need for 'communication and collaboration to develop health informatics as a distinct academic and professional endeavour with its own body of knowledge and skills' (Brittain, 1993, p. 33).

The lack of institutional practices and relationships to control the production of health informatics skills and knowledge also indicated an absence of communities of interest at this time. A number of authors emphasised the need for core knowledge, common skills, and a shared approach to the education of health informatics professionals: 'It is timely to work towards a nationally agreed set of competencies, skills and knowledge for information workers in all facets of healthcare' (Brittain, 1993, p. 30). This pointed to an intention to constrain health informatics activity within disciplinary parameters. However formal mechanisms for defining appropriate knowledge and skill sets, establishing academic standards, or overseeing professional accreditation procedures, were absent. Instead, several authors discussed these issues in terms of sub-sets of professional education requirements for other health professionals rather than as a distinct academic and professional knowledge area. Credentials on which conference participants based their authority to speak further highlighted the diverse nature of the field. Authors at the 1993 conference cited academic and professional credentials from a range of disciplines, including

medicine, nursing, computing, information technology, law and education. The few PhD students listed in the proceedings were aligned with disciplines of computing, information systems, or health, rather than specifically designated health informatics or e-health disciplines. The conference chair, who was also the president of HISA, was not awarded a PhD in health informatics until 1995. While the keynote speaker had the status position of President of the International Medical Informatics Association, her discipline was continuing medical education. Plenary speakers were experts in disciplines other than health informatics.

Mechanisms to control the dissemination of approved knowledge were similarly without specific disciplinary parameters. Two channels for knowledge dissemination were identified. These were the HIC conference and a bi-monthly magazine, *Healthcare Informatics in Australia*, published by HISA. The conference was the main conduit for dissemination of knowledge. The HIC93 Conference Committee chose not to impose standards on the content or format of contributions to this conference, deciding instead ‘to accept all submitted papers to determine what information was out there’ (Edgecumbe, 1993). As indicated in Appendix 1, papers were wide ranging in their content and authors used a variety of formats and styles ranging from personal anecdotes, to opinion and discussion papers, to formally structured and referenced scientific research papers. The first publication of the bi-monthly *Informatics in Healthcare Australia* journal was November 1992. This was a non-refereed journal which distanced itself from the rigours of academic publications by stating that ‘all persons interested in any aspect of informatics in health are invited to submit articles for publication. All articles will be processed through an Editorial panel process, but not a formal referee process as with learned journals’ (*Informatics in Healthcare Australia*, 1993).

While there was little to indicate the presence of health informatics communities of interest at the time of the 1993 conference, all six discourses were evident in the conference proceedings. In the absence of identifiable institutional processes and relations, the strength of each discourse was determined by the extent to which they dominated the texts. The analysis showed that the health technology, management and nursing informatics discourses had a greater presence than the clinical informatics, scholarly or population discourses. The analysis suggested that the health technology and nursing informatics discourses were able to capitalise on links with academic disciplines of computing and nursing. Authors of papers dominated by the nursing informatics discourse were located in schools of nursing, while technology dominated papers originated from academic departments of computing and information technology or information management departments in health services. These links provided a relatively large body of academic and professional literature, established practices, and knowledge experts for the discourses to draw upon. This enabled the discourses to have an immediate presence within the fledgling discipline of health informatics. The clustering of papers dominated by these discourses emphasised that health informatics was an area of interest within other disciplines or professions.

7.2.2 1999-2001: Groups of like-minded individuals

An academic discipline of health informatics was more clearly identifiable during this period. Seven universities had designated health informatics or e-health schools, departments or faculties and most of these contributed multiple papers to the conference. Authors not located within designated health informatics academic sites were located in faculties and schools of nursing, medicine, rural health, public health, information systems and computer science (Table 7.2).

Table 7.2 Conference papers: Academic sites, 1999-2001

Academic Institution	Faculty/school/division
CSIRO	Telecommunications and industrial physics
ANU	National centre for epidemiology and population health
Australian Catholic University	Faculty HS
University of Southern Queensland	Nursing
University of Queensland	Centre for Online health
University of Central Queensland	Faculty of informatics and communication
Griffith University	N/A
Queensland University of Technology	N/A
University of Western Sydney	School of computing and information technology
University of Wollongong	Scholarly School of information technology & comp science Centre for cooperative research
UNSW	School of info sys, technology and management Centre for health informatics
Macquarie	Division of information and communication sciences
NSW University of Technology	N/A
Monash	Centre for Medical Informatics
University of Melbourne	Department of General Practice – <i>no dominant discourse</i> Department of Psychiatry School of postgraduate nursing
La Trobe	Population/scholarly School of Public Health Dep't computer science and computer engineering National Centre for Classification in health
University of Ballarat	Australian healthcare messaging laboratory, Collaborative centre for e-health
University of Adelaide	Multiple – one year – no dominant discourse General practice Pathology FHS _ Health Informatics Unit
Flinders	General practice

Authors in health services were located in a range of sites, including central administration, hospitals, area health services and community faculties. No health service contributed more than a single paper (Table 7.3).

Table 7.3 Conference papers: Health service sites 1999-2001

Health Service	Department or Division
Australian Antarctic division	
Queensland Health	Royal Brisbane Hospital Department of telehealth services Telemedicine Network Wesley hospital
NSW Health	Information management and asset services Wentworth area health service SSWAHS John Hunter Hospital Nursing informatics Blacktown-Mt Druitt Health
Vic Health	St Vincent's Hospital Alfred Hospital – ambulatory/community services Peter McCallum Western Hospital Footscray Mildura Base hospital Computer services Department
Ballarat Division of General Practice	
South Australian Department of Human Services	Royal Adelaide Hospital Institute of medical and veterinary science Women's and Children's hospital
WA Health	Sir Charles Gardner Hospital WA
	Wilcannia Health
St John of God Healthcare WA	N/A
Territory Health Services	N/A

This suggested the beginnings of communities of interest, primarily located within academic institutions and supported by ongoing interest from individuals from a range of professions and disciplines. At the same time, the level of collaboration indicated that communities were at a relatively low level of interaction. Fifty-nine papers were the work of single authors. Of the twenty-eight jointly authored papers, five were co-operative efforts between departments or schools within the one institution, while the remaining twenty-three were jointly written by authors from different institutional types.

The health informatics community represented itself as consisting of diverse interest groups. James, the 2001 Conference Chair, stated that 'there has been a growing recognition of the diversity of professional and employment backgrounds of those now involved in health information management and technology. There is clearly a need for collaboration and the development of

strong, ongoing relationships’ (James, 2001, Foreword). HISA documentation also referred to the diversity of the community, stating that HISA ‘promotes and co-ordinates the activities of these organisations and links groups and individuals throughout the field’ (1999). Yet, as the analysis of author location indicated, small and localised communities existed within this diverse field. These were largely located within the academic communities grouped around designated health informatics or e-health departments (Table 7.4). The discipline appeared to be at the point where ‘groups of like-minded individuals were beginning to organise themselves into intellectual fields, becoming located in departments, research groups, schools, faculties’ (Hassan, 2011; Introna, 2003). Different discourses were identified as shaping each of the communities. The nursing informatics discourse was strong in the Faculty of Informatics and Communication, Central Queensland University. The scholarly and health technology discourses dominated the Centre for Health Informatics at the University of New South Wales, while the scholarly discourse was evident at the Centre for Medical Informatics, Monash University. The management discourse, while not linked with a particular location, was dominant across all health service and commercial sites.

Processes for controlling the production and dissemination of health informatics knowledge, and mechanisms for accrediting knowledge experts, were evident during this period. All designated academic departments and schools of health informatics were involved in health informatics research and/or education programs (Table 7.4).

Table 7.4 Health informatics centres and programs: 1999-2001

Institution	Centre	Education program
University of Queensland	Centre for Online health	
Central Queensland University	Faculty of informatics and communication	Bachelor of Nursing Informatics Graduate Diploma in Health Informatics Master in Health Informatics
University of Wollongong	Faculty of informatics	Master of Health Informatics PhD in health informatics by

		research
University of New South Wales	Centre for health informatics	Master of Public Health (Health informatics) by research PhD in Health Informatics by research
Monash University	Centre for Medical Informatics	Graduate Certificate in Health Informatics Graduate Diploma in Health Informatics Masters of Health Informatics
University of Ballarat	Collaborative centre for e-health	
University of Adelaide	FHS _ Health Informatics Unit	
CSIRO	E-Health Research Centre	
University of Sydney		PhD in Health Informatics by research
University of Tasmania	Rural health	Health Informatics education and training project

A HISA report *Health Informatics Education* (2002) identified an additional eighteen health informatics units of study in a range of academic programs in eleven universities during this period (Table 7.4). This report noted varying approaches in the content and structure of health informatics within these programs. ‘This probably reflects the varying location of health informatics within educational institutions. That is, whether health informatics is located within medical, nursing or health faculties or located in computing faculties’ (2002:18). This study argues that these varying approaches point to the presence of different discourses. Further evidence of institutional support for the academic discipline was indicated by the (albeit small) number of conference papers that were supported by postgraduate or other research grants. This suggested that the health informatics community/health informatics discourses were beginning to exert influence with ‘enough people - that matter’ (Introna, 2003, p. 236). Introna adds that ‘the reference to those “that matter” is a reference to the sort of people who are in a position to make decisions about funding, promotions, publications, and so forth’ (Introna, 2003, p. 236).

While academic research and education programs allowed the community some control over the production of health informatics skills and knowledge, this influence was limited. Mechanisms such as course advisory committees had some authority to oversee programs but their focus remained within a particular

institution rather than expanding across the discipline as a whole. This allowed different discourses to shape academic programs in the various institutions. At the same time an emerging network of control was indicated with the acknowledgement of HISA as national governing health informatics body in 2000 (HISA, 2012).

While the community had limited control over the production of knowledge, mechanisms for controlling the dissemination of approved knowledge were more apparent. Conference abstracts were reviewed by expert panels in accordance with DEETYA guidelines: submitted and printed abstracts were subject to double blind peer review by experts in the field of health informatics (HIC2001 Conference Proceedings, p. i). Conference presentations were differentiated in terms of keynote speakers, concurrent sessions and poster presentations, with more important (i.e. approved) knowledge and speakers presented as keynote addresses to the conference as a whole and speakers lower in the status hierarchy presenting their work in concurrent sessions or as posters. These processes pointed to the growing influence of the scholarly discourse. This was also reflected in the *Journal of Healthcare Informatics* (formerly *Healthcare Informatics in Australia*) which had implemented a 'refereeing process consistent with learned journals' (Vol. 7, 1998).

Although largely confined to the academic institutions, a hierarchy of status positions based on health informatics qualifications and expertise was also identified at this time. While many conference officials and participants continued to base their authority to speak on a range of academic and professional credentials including medicine, nursing, computing, information technology, law and education, many also referred to their professional roles of 'Director, Health Informatics', 'Director, Centre for Online Health', and 'Clinical Informatics Co-ordinator'. Health informatics academic qualifications were also beginning to appear with a number of doctoral students contributing

to the conference. Senior academics in the various centres had health informatics qualifications, including PhDs. Health informatics research and education programs were producing graduates with health informatics qualifications, establishing the link between authority to speak and the possession of 'expert' disciplinary knowledge. Several speakers from the inaugural conference now based their authority to speak on health informatics qualifications and expertise. While conference chairs were not from designated health informatics environments, several keynote speakers and members of the expert review panel were identified as health informaticians.

The relative influence of the discourses had changed since the 1993 conference. The management, scholarly and health technology discourses were more dominant while the nursing informatics discourse was less influential. Academic institutions had established themselves as the source of expert knowledge production and dissemination. More than half of the conference papers originated from academic institutions. The influence of the scholarly discourse was evident in the processes and guidelines applied to academic teaching and research programs. These conformed to academic practices highlighting the increasing influence of the scholarly discourse across the academic health informatics community as a whole. This increasing influence was also evident in the HISA report lamenting the lack of control mechanisms for course development and called for the implementation of curriculum guidelines (2002, p. 25). Some resistance to this discourse was also identified. The report noted reservations from 'some groups regarding the potential prescriptiveness of any such guidelines' (2002, p. 25). As discussed, the influence of the scholarly discourse was also evident in governance processes of the conference. In addition to this wider influence, conference papers pointed to the discourse community centred around the Monash University Centre for Medical Informatics as focussed on issues delineated by the scholarly discourse (Appendix 1). The analysis identified a nursing informatics

community of interest centred around the University of Central Queensland. This community offered health informatics education and research programs (Table 7.4). However, the nursing informatics discourse had contracted to Queensland, primarily within the academic institutions. It was not a strong presence elsewhere. The clinical discourse had a minor presence but with no identified community of interest. Authors were located primarily in clinical environments in health services or universities and based their authority to speak on medical qualifications rather than health informatics qualifications. This suggested that while the clinical discourse operated within the health informatics community, it remained an area of interest within the discipline of medicine. The populations discourse was even more clearly an interest group within the public health community. The few papers emphasising this discourse came from the School of Public Health at La Trobe University or the National Centre for Epidemiology.

7.2.3 2006-2009: Communities of interest

The 2006-2009 conference papers pointed to the academic discipline of health informatics having established itself as an accepted field of endeavour. A strong allegiance to the health informatics community was evident in the texts where, rather than being concerned with the diversity of groups involved in the field, authors spoke of the range of activities that health informaticians were involved in. Discussions about health informatics issues and health informatics research replaced the earlier emphasis on the need for collaboration. This change of focus pointed to a sense of shared understanding around what constituted valid health informatics knowledge and what constituted a valid approach to seeking and using that knowledge. The level of collaboration evident in the papers is also indicative of a sense of community. In contrast to the inaugural 1993 conference, where most papers were presented by sole authors, the majority of papers in this later period were jointly authored and reported on cooperative efforts to implement a range of projects, programs and activities (Appendix 1).

While this may have suggested a discipline developing shared understandings and a shared purpose, the analysis pointed to the influences of several communities of interest supporting different discourses. Authors in 1993 were situated across 12 universities in six states, five public health and three private health organisations and several commercial sites (Table 7.1). By 2009, while the number of papers from academic institutions comprised more than half of the overall proceedings, these originated from eight universities in three states, with the majority of authors located at the University of Sydney, the University of New South Wales, the University of Wollongong, the University of Melbourne and the CSIRO. These five institutions were identified as ‘hubs’ around which interested groups of academics and professionals congregated. Of these hubs only the University of New South Wales retained the leading role it had occupied in 1999-2001. These hub institutions offered education and/or research programs in health informatics and e-health. In developing these programs, they had developed collaborative links and partnerships with other academic institutions, government instrumentalities, healthcare organisations and, in some instances, commercial organisations (Table 7.5). Collaborative relationships were indicated by listing and acknowledging partners in academic and professional literature and on websites.

Table 7.5 Communities of Interest, 2006-2009

Institution	Centre	Collaboration partners
CSIRO/Queensland government partnership	E-Health Research Centre	Queensland University of Technology Griffith University Queensland Health <ul style="list-style-type: none"> • Queensland Ambulance Service • Royal Brisbane & Women’s Hospital • Prince Charles Hospital • Southern District Emergency Network • Gold Coast Hospital
University of Wollongong	Faculty of Informatics	Flinders University Queensland University of Technology National Inst Clinical studies UNSW NSW Health <ul style="list-style-type: none"> • South East Sydney/Illawarra Health Service
University of New South	Centre for Health	University of Wollongong

Wales	Informatics	University of Sydney NSW Health <ul style="list-style-type: none"> • Westmead • SSWAHS
University of Sydney	Health Informatics Research and Evaluation Unit	UNSW Centre for Health Informatics HealthCube Management
University of Melbourne	No designated health informatics Centre Authors were located within the Faculty of Medicine	Bond University Macfarlane Institute for Medical Research and Public health Global Health Informatics Vic Health <ul style="list-style-type: none"> • Barwon Health • Austin Health

The analysis pointed to different discourses dominating within each of these communities. This was determined through the analysis of texts that included conference papers and information and promotional documents issued by the institutions. Conference papers indicated that the CSIRO Australian E-Health Research Centre in Queensland was dominated by the health technology discourse. Papers from the UNSW and Wollongong communities reflected the technology and scholarly discourses, while the technology discourse was dominant within the University of Sydney. The clinical informatics discourse was dominant within the University of Melbourne group. Rather than being located in a health informatics or e-health centre, the community was based in the Faculty of Medicine and Dentistry with contributors to the conference using medical qualifications as their authority to speak (Appendix 1). Goals and mission statements supported these various discourses:

- Australian E-Health Research Centre (CSIRO, Queensland government): ‘aims to develop and deploy leading-edge ICT innovations in the health care domain to improve service delivery in the Queensland and Australian health care systems’ (CSIRO Australian E-Health Research Centre, 2012).
- University of Sydney: ‘Health Informatics is concerned with the development, dissemination and use of information and communication technologies in health care’ (University of Sydney, 2011).

- ‘The Centre of Health Informatics (CHI) at the University of New South Wales is building an international reputation as a research leader in the application of information technology to healthcare’ (UNSW Centre for Health Informatics, 2012).
- University of Wollongong: ‘To provide the highest quality education to graduates who will take leadership roles in the information and communication technologies; subsumes health informatics within the broader field of informatics’ (University of Wollongong, Faculty of Informatics, 2012).

Thus, during this period, discourse communities were engaged in efforts to ‘construct meanings in line with their views and interests’ (Gastaldo & Holmes, 1999). The political nature of this process was indicated by changes in conference participation at the University of New South Wales (Appendix 1). While this hub site contributed multiple papers to the conference in 2006, none were presented in 2008 but multiple papers were again presented in 2009. In 2008 a number of staff from the University’s Centre for Health Informatics had relocated to the University of Sydney. These staff returned to the University of New South Wales in 2009. The number of papers from the University of Sydney declined in 2009 (Appendix 1). This reinforces the Foucauldian view that development of disciplinary discourses ‘is a political question of funding, institutional arrangements and the like. They are not a discipline because they got it right, but because they have convinced enough people, and aligned themselves with enough people that matter’ (Introna 2003, p. 236).

As with the 1999-2001 conference proceedings, there were no identifiable geographically-based communities of interest around health care organisations, although there was evidence that state-wide discourse communities had emerged. Queensland Health was part of the CSIRO E-Health discourse community. New South Wales State Health reflected the clinical informatics

discourse and to a lesser extent, the management discourse, while the management discourse was dominant in Vic Health. Commercial sites were dominated by the technology and management discourses.

The analysis of institutional processes and relations highlighted the influence of discourses within each discursive community, but also pointed to the power of the scholarly discourse in shaping discipline wide activity. Different understandings about health informatics may have operated in each discourse community. However since all communities were located in the academic environment, they were subject to established academic expectations (discourse) relating to knowledge development and dissemination, accrediting knowledge experts and promoting the discipline. These expectations supported the power of the scholarly discourse. Evidence of the influence of this discourse was seen in the increasing discussion around the need for a health informatics education framework. As Hovenga noted, ‘there is a need to be able to define a Health Informatician by their graduate attributes’ (2004, p. 55). While institutions offering academic programs in 1999-2001 had been subject to local guidelines and standards for academic course structure and content, they were largely independent. There were no widely shared understandings about appropriate course structure or content. During the 2006-2009 period, initiatives for the introduction of discipline wide standards for education and professional practice were introduced. HISA compiled a Review of the Australian Health Informatics Workforce (2009), which ‘set out the scope and structure for a health informatics workforce’ (2009, p. 3). Following the release of this review, the Australian College of Health Informatics formed the Australian Health Informatics Education Council (AHIEC) to ‘ensure a coherent, comprehensive approach to quality health informatics education and training in Australia’ (AHIEC, 2011). In 2011, the Council released the document *Health Informatics: Scope, Careers and Competencies*. The document:

defines the scope of Health Informatics, identifies areas of Health Informatics specialisation, roles and career options, defines Health Informatics

competencies, and identifies the Health Informatics skill sets required by people working in the healthcare industry (AHIEC, 2011, p. 4).

The success of the Education Council project enabled the scholarly discourse to impose conformity about what knowledge is valid, how it is acquired and how it is shared. This control was extended in 2012 with the establishment of the Australian Health Informatics Certification Program (AHICP) Project. The purpose of this project was to develop and implement a certification program for health informatics professionals to be implemented from 2013 (HISA, 2012). These measures provided the scholarly discourse with the power to oversee the education and accreditation of new graduates and professionals, thereby reinforcing existing status hierarchies of expertise and authority. These hierarchies, based on health informatics qualifications and expertise, were present during the 1999-2001 period, but were more widely imposed during 2006-2009. This was evident in the conference proceedings where the terms health informatics or e-health were increasingly used to designate academic qualifications and professional positions. There had been in the period between the 1999/2001 conferences and the 2006-2009 conferences had seen a progression of authors from the status of health informatics students to acknowledged experts with accepted qualifications and status positions. This status hierarchy was reinforced by membership requirements for the College which stipulated specified levels of membership comprising Fellow, Full Member, Associate Member and Student Member. These were differentiated on the basis of contribution to the discipline of health informatics, years of practical experience and qualifications (Ref). Membership requirements absorbed professionals without academic qualifications within the hierarchy. ACHI was able to link its control of status positions to disciplinary knowledge by stipulations such as 'to be eligible for admission to the College as a Student Member, a person must be enrolled in a Health Informatics program of study recognized by ACHI' (ACHI Application form, 2012). The College claims expertise and authority to speak for its members. 'The credentialed Fellows and

Members of the College are national and international experts, thought leaders and trusted advisers in Health Informatics' (ACHI, 2011).

The increasing influence of ACHI demonstrated the power of the scholarly discourse. HISA was a professional organisation with traditionally much more open membership parameters than ACHI: 'Membership is open to all individuals and organisations with an interest in e-health and health informatics' (ACHI, 2012). HISA was the first, and for several years, the leading health informatics organisation in Australia. During the period 2006-2008, although HISA continued to promote the discipline and the profession, ACHI became increasingly influential, claiming authority to speak on behalf of the health informatics community: 'ACHI has the expertise to advise government and the professions on eHealth matters' (2009). ACHI reinforced its authority through affiliations with a range of health informatics and other professional groups, including the International Medical Informatics Association, Health Informatics New Zealand, Standards Australia and more generic peak bodies such as the Australian Council of Professions. Towards the end of this period ACHI expanded its influence, becoming The Australasian College of Health Informatics, the professional body for health informatics in the Asia-Pacific region.

The scholarly discourse also controlled discipline-wide processes for the dissemination of knowledge. The HIC conferences continued to be an important mechanism for the dissemination of knowledge. All papers submitted to the conference, be they research reports, descriptions of projects or discussion papers, were structured according to the accepted standards of an academic scientific paper. Papers were double peer-reviewed according to DEST publication standards and ranked in categories ranging from full refereed papers to poster presentations (HIC08 Conference Proceedings). While HISA continued to manage the overall conference organisation, scientific program

committees, dominated by academics, managed this refereeing process. Academic knowledge production was privileged within the conference. The majority of papers submitted by authors from academic institutions were accepted for presentation at concurrent sessions. Most papers from commercial sites were allocated to the poster category, generally considered a lower status than full papers. Many of these presentations were descriptions of projects that had been implemented. They generally did not link to academic research or teaching programs or address theoretical or implementation issues identified in academic programs (Appendix 1).

The *electronic Journal of Health Informatics* was the second major channel for information dissemination. This journal was established by ACHI and replaced the HISA sponsored *Journal of Healthcare Informatics*. ACHI describes the publication as ‘our journal, dedicated to the advancement of Health Informatics and information technology in healthcare’ (*electronic Journal of Health Informatics*, 2011). This was a peer reviewed journal with an editorial board claiming authority to monitor and judge submissions to ensure they meet the standards set by the editorial board. ‘*eJHI* is an international Open Access journal committed to scholarly excellence and has a global readership in all health professions and at all levels’ (*electronic Journal of Health Informatics*, 2011). Manuscripts submitted for publication were peer-reviewed according to DEST Higher Education Research Data Collection criteria. Thus, the scholarly discourse disciplined the dissemination of knowledge by controlling these channels.

7.3 Relative influence of the discourses

7.3.1 An emerging academic discipline

At the time of the inaugural conference, health informatics was a topic of interest within a number of referent disciplines rather than a discipline in its own right. This was indicated by a dearth of identifiable communities of

interest, the diversity of strategies used for production and dissemination of knowledge, the absence of an identifiable status hierarchy of experts and institutional processes and relations that could be linked back to the reference disciplines. At this time six discourses were evident in the field, with the health technology, management and nursing informatics discourse having the greatest presence. In 1999-2001 an academic discipline of health informatics was more clearly identifiable. Institutional support included designated departments of health informatics and e-health conducting education and research programs. The beginning of a status hierarchy based on health informatics expertise was evident and shared understandings about the production and dissemination of health informatics knowledge were beginning to emerge. The relative influence of the discourses had changed since 1993, with the health technology and management discourses being joined by the scholarly discourse in shaping the processes and relationships while the influence of the nursing informatics discourse had declined. By 2006-2009, health informatics was identifiable as an academic discipline. Academic research and teaching programs, an established status hierarchy supported by professional organisations, and accepted mechanisms for the production and dissemination of knowledge were evident. At the same time, the health informatics community was not united, but comprised a number of discourse communities, each with their own understandings about the object *health information*. The six discourses identified in the inaugural texts were still in evidence, with the scholarly, management and health technology discourses exerting the greatest influence. Table 7. Appendix 2 lists the discourses associated with the papers. While a text may contain multiple discourses, the parameters around conference papers, such as required format and word length, resulted in the majority of papers being largely being dominated by one discourse.

7.3.2 Relative influence of the discourses

In 1993, the scholarly discourse was marginal. This was indicated by the limited presence of the discourse in the conference texts and a lack of institutional processes and relations indicating the presence of the discourse. While this could be construed as indicating the pre-disciplinary state of health informatics, it also pointed to the limited influence of the scholarly discourse. By 2006-2009 the influence of the scholarly discourse was much more in evidence. This was indicated not so much in the content of conference texts as in the way the discourse controlled the social practices and social relations of both the conference. In the broader health informatics community, the scholarly discourse had established an institutionalised network of influence that incorporated national organisations, university-based teaching and research programs, academic journals and the conference. While HISA continued to represent the health informatics community, the Australasian College of Health Informatics (ACHI), formed in 2002, was increasingly influential. Through ACHI, the scholarly discourse was able to impose a discipline-wide hierarchy of status positions linked to academic qualifications. HISA reinforced this with its professional accreditation program, which is expected to be introduced in 2013. The official documentation of these organisation points to the influence of the scholarly discourse. Documents from both groups refer to the need for skilled health informatics professionals, with ACHI in particular speaking of ‘informatics knowledge gaps’, ‘research strategies’ and ‘accreditation strategies’. The role of academic institutions in addressing these issues is emphasised: ‘the gaps in health informatics knowledge and competencies in the current workforce must be addressed by educational institutions’ (ACHI, 2008). In addition, the College claims the authority to speak on behalf of the community. ACHI is represented as ‘the professional college of experts to develop and maintain a training and accreditation strategy’ (ACHI, 2009) and ‘national and international experts, thought leaders and trusted advisers in Health Informatics’ (ACHI, 2010). These statements reinforce the aspirational

goal of the scholarly discourse to establish the discipline of health informatics as the acknowledged authority. The success of the discourse is indicated by its presence in the texts and also by the institutional processes and relationships that were identified in the wider community. These include the establishment of organisations such as National E-Health Transition Authority (NEHTA) in 2004. NEHTA, jointly funded by state, territory and Commonwealth governments, was intended to 'advance the e health agenda through development of e health standards, clinical terminologies and patient and provider identifiers' (Jolly, 2011). More recently, the federal Labor government introduced its national e-health strategy 'calling for a national strategic framework and plan for national coordination and collaboration to be put in place' (Jolly, 2011). These programs legitimated the emerging discipline of health informatics, with terms such as 'health informatics' and 'e-health knowledge' emphasising this specialised area of expertise. Successive government policies and programs emphasising the need for a skilled health informatics workforce reinforced this perception. These programs also acknowledged the role of research and development, a key activity for an academic discipline. This institutionalisation of health informatics pointed to the success of the scholarly discourse in achieving its aspirational goal.

The success of the management discourse was indicated by its persistence in conference texts across all years included in the study. The strong presence identified in the inaugural conference texts only increased in later texts (Appendix 2). However, the real influence of the discourse was its successful colonisation of other discourses, particularly the less influential nursing informatics and populations discourses. Managerial themes in the nursing informatics discourse advocated use of clinical nursing systems for such purposes as routine monitoring, evaluating and benchmarking nursing practice. Managerial concepts such as value-adding, cost effectiveness, nursing efficiencies, and cost-benefit analyses were used to support nursing informatics.

Similarly the populations discourse incorporated management discourse concepts and themes regarding the use of health information for policy development, planning, management, monitoring, and evaluation of health care systems. The populations discourse justified national data collection practices for the development of uniform standards and benchmarks, arguing that it provides ‘the only reliable basis for describing and analysing the health system,’ which is represented as a pre-requisite for the provision of better services. Other discourses resisted encroachment by the management discourse with varying degrees of success. The clinical informatics discourse continued to refer to patients rather than consumers, emphasised medicine as both an art and a science, and spoke of clinical care rather than business efficiencies. Yet the clinical informatics discourse adopted the managerial representation of health care as managing patients rather than treating them. The scholarly discourse also incorporated managerial themes in later texts. Rather than being located within an identifiable discursive community, the management discourse was located across a range of sites, primarily within management and business divisions of health organisations but also in clinical and nursing divisions as well as some academic and commercial sites. Its major area of influence was within the health services in the Queensland, New South Wales and Victorian health departments where it garnered the institutional support to shape the practical manifestation of health informatics. This was indicated by an increase, over the period of the study, of departments and sections designated as health informatics and e-health, and by the increasing use of ‘management speak’ in documentation about health information management. The HISA and ACHI texts incorporated concepts and themes from the management discourse in their official discussion, submissions and other commentaries. These documents discuss health informatics in the context of ‘the crisis in healthcare’, ‘unprecedented pressures on health systems’ and ‘mounting demands for services’: ‘There is a looming crisis in the health care system from an unprecedented simultaneous bulging in demand and reduction in workforce’

(HISA, 2007). The discussions emphasise ‘performance’ to produce ‘products’, ‘services’ and ‘deliverables’ that are ‘outcomes focussed’ and will bring ‘improvements in efficiency, safety and quality’.

The health technology discourse was an enduring discourse with a strong presence in conference papers across all years of the study (Appendix 2). This discourse successfully colonised other discourses. This was not unexpected. Information and communications technology is undeniably a key, and increasingly essential, tool for health informatics. The concepts could be expected to appear in all discourses. So successful has the discourse been, however, that technology has become a key focus of the health informatics discipline. Recent definitions of the discipline link health informatics with technology, implying that any issue of health information management must necessarily involve a technology solution. The University of Wollongong, for example, states that its Master of Health Informatics program is ‘designed to provide IT professionals with a better understanding of the specifics of health informatics and provide health professionals with a better understanding of IT within their industry’ (University of Wollongong Faculty of Informatics, 2012). While supporting and incorporating the academic standards and practice of the scholarly discourse, the health technology discourse specifically utilises the objective, rational knowledge production and dissemination practices of modern science, thus aligning itself with the dominant approach to knowledge management in modernity. In addition to the University of Wollongong, the health technology discourse had established institutional support in three academic-based communities of interest. Despite, or perhaps because of its influence, there was evidence of resistance to the technology discourse. While continuing to be a dominant discourse within the academic discipline, the focus on technology was regularly challenged as being too narrow, and for neglecting social and organisational aspects of health information management. Coiera (2004, p. 1197) was critical of the dominant emphasis on ‘the sacred ground of

health informatics: computers, the web, information architectures, the electronic health record, and heroic challenges such as the creation of enormous terminology systems' which result in the neglect of 'the profane ground of health informatics, the world of politics, culture and persuasion' (Coiera, 2004, 1199). Resistance, while not systematic, was evident in statements such as:

- Information systems is still dominated by data-driven methodologies, tools and techniques that produce technical solutions to organisational problems (Atkinson et al., 2001)
- The informatics model (of data, information and knowledge) is a simplistic way to conceptualise a complex process (Georgiou, 2002, p. 130)

The decreased influence of the technology discourse was indicated in changing government policy, particularly the HealthConnect program and the National E-health Strategy (2008). The HealthConnect program, introduced in 2002 to develop an electronic information superhighway changed direction in 2005, when it began to be referred to as an 'overarching national change management strategy' (DoHA, 2012). Within the National E-health Strategy e-health was defined as 'the means of ensuring that the right health information is provided to the right person at the right place and time in a secure, electronic form for the purpose of optimizing the quality and efficiency of health care delivery' (2008, p. 1). While acknowledging technology as a tool, this statement focused on health information management. This pointed to the health technology discourse as less influential than the scholarly or management discourses in this later period. This was reinforced by the analysis of HISA and ACHI texts. Technology was still acknowledged as an integral element of health informatics: 'a core enabler of improvement in the quality, safety and efficiency of health services is the appropriate investment in and use of information technology' (HISA, 2008). However the centrality of technology, and therefore the health technology discourse was challenged. Challenges ranged from statements that emphasised 'technology-neutral' responses to issues, to the coupling of technology with social and organisation strategies to resolve information

management issues to the blunt statement ‘Technology is NOT our problem’ (ACHI, 2007).

The populations discourse was always marginal. From the inaugural conference, its presence was evident but minimal, with no identified discursive community. Issues and themes identified within the discourse paralleled those addressed in the discipline of public health, while authors supporting this discourse were, on the whole, located within existing schools, faculties or divisions of public health (Appendix 1). While the issues addressed within the discourse are addressed in government and health department policies and programs, this may be more a result of the efforts of the public health discourses than of the health informatics populations discourse. It appeared that the populations discourse performed a support role for the more dominant health informatics discourses. The discourse supported the management discourse, linking quality care, effective management and timely and accurate access to data and information as essential for effective and efficient health care. It also supported the technology discourse with its emphasis on the increasing capacity of information technology for manipulation of data.

The analysis suggested that the clinical informatics discourse was a relatively influential discourse. This was indicated by the ongoing and increasing presence of the discourse in conference texts, and by an emerging community of interest. While the dominant discourse in less than ten per cent of conference papers in 1993, the clinical informatics discourse had become the dominant discourse in more than twenty per cent of papers in the 2006-2009 period (Appendix 2). In addition a discursive community was identified at the University of Melbourne, although this community was part of the Faculty of Medicine and incorporated authors from a range of general and specialist medical fields. Thus, while the clinical informatics discourse appeared within the health informatics texts and incorporated the academic standards and

practices of the scholarly discourse, it retained a degree of independence from the other health informatics discourses, resisting colonisation or infiltration by either the health technology or the management discourses. While it shared some issues with the health technology discourse, the clinical informatics discourse constructed technology on its own terms as an increasingly essential tool to assist clinical care. Similarly, while incorporating the managerial dictum of managing rather than treating patients, the discourse emphasised quality care and positive outcomes rather than cost-effectiveness and efficiencies. The focus on clinical issues rather than on broader themes within the scholarly, management and health technology discourses resulted in the clinical informatics discourse looking inwards to the medical profession.

The initial analysis suggested that the nursing informatics discourse was less successful than the scholarly, health technology or management discourses. This was indicated by the declining presence of the discourse in conference texts. In early texts upwards of twenty per cent of papers reflected the nursing informatics discourse but by the 2006-2009 conferences, the discourse had all but disappeared from the proceedings. In 1999-2001, a small community of interest appeared to be forming within tertiary institutions in Queensland but this was not evident in the 2006-2009 texts. None of the five discursive communities identified in the later conference papers supported the nursing informatics discourse. However the discourse was not as marginal as first appeared. While not a strong presence in the health informatics texts, it appeared as a sub-field within the nursing discipline. A nursing informatics conference has been held immediately prior to the more generic health informatics conference for at least a decade. This pointed to the nursing informatics discourse connecting to the health informatics community but at the same time retaining a separate presence as a sub-discipline of nursing. Nursing informatics may be viewed as both a specialty in nursing and a special interest group of health informatics. The success of the nursing informatics

discourse within the discipline of nursing was indicated by the development of nursing informatics competency standards for inclusion in nursing curricula, and the introduction of nursing informatics units within undergraduate and postgraduate programs. The nursing informatics discourse supported the health technology discourse, particularly in earlier texts, where nursing informatics was represented as being very much about computers and technology. It also appeared that the discourse was colonised by the management discourse.

7.4 Conclusion

The health informatics community between 1993 and 2009 was a fluctuating set of complementary and competing beliefs, motivations and manipulations rather than an internally consistent body of knowledge and practices. During this period the more dominant management, health technology and scholarly discourses colonised other discourses. They also interacted with one other. Later conference papers in particular pointed to a degree of integration occurring between the dominant discourses. Similarly, official documentation from the organisations peak bodies pointed to these discourses interacting to shape the academic discipline of health informatics. No critical discourse was identified in the analysis although a number of statements pointed to critical stances adopted by some individuals in diverse locations. These few texts are listed in Appendix 3. The lack of critical discourse has implications for the way the health informatics community approaches issues around the use of personal health information. The next chapter focusses specifically on the way the discourses constructed issues relating to personal health information management.

Chapter 8: Constructing personal health information

8.1 Introduction

Anyone who works in the healthcare sector understands the importance of maintaining confidentiality with a patient's personal and often highly sensitive information (Croll, 2008, p. 1).

This chapter addresses the last two questions posed by the study: *How do the health informatics discourses construct issues around use of personal health information?* and *What might be the implications of this?* The answers to these questions are important. The academic discipline of health informatics is strategically located to influence decisions about the use of personal health information in Australia. These decisions currently occur within the parameters established by the privacy framework. The parameters of the framework are built on the construct of personal information as a privacy/public interest balance. This construct has been criticised as inadequate for managing function creep, a phenomenon argued to occur 'at a systemic level (institutions, social practices, fabric of modern life), not at the level of private space' (Regan, 2007, p. 497). Critics argue that alternative constructs need to be utilised to address the issues of social sorting, discrimination and social control that are associated with function creep (Jacobs, 2006; Juntti & Turnpenny, 2009; Lyon, 2007c; Shaw & Greehalgh, 2008). A discourse establishes the parameters within which a topic may be addressed. It also limits alternative approaches to the topic. Therefore, the capacity of the health informatics community to contribute to the discussions around the privacy/public interest construct and function creep is dependent on the parameters established by the discourses shaping the discipline. The analysis identified a commonality in the way the discourses represented issues relating to use personal health information. Within these shared parameters each discourse constructed priorities, issues and solutions in the context their specific construct of health informatics. The discussion

outlines the common understandings identified by the analysis. It then describes the way these understandings were applied within each discourse. The final section of the chapter considers the implications of these understandings about privacy for the discipline. For this final phase of the study, the analysis returned to the conference texts but supplemented them with the 2008 special edition of the *electronic Journal of Health Informatics* which focussed on privacy and security issues. The analysis grouped texts according to which discourse dominated each paper or article. Each set of texts, representing a specific discourse, was then analysed to identify the way themes and strategies grouped objects and concepts to construct the specific issues around personal health information use.

8.2 Constructing the problem

Discourses are generally represented as competing to impose their understanding or version of appropriate knowledge. However, where issues of privacy and security were concerned, the health informatics discourses were not able to be differentiated. All six discourses incorporated the privacy/public interest construct of the Australian privacy framework. This was indicated by recurring statements that emphasised ‘federal, state and organisational’ regulations’, ‘compliance with regulatory requirements’, projects being ‘subject to privacy principles’, and the importance of ‘not violating privacy constraints’. These statements appeared in all six discourses. This shared construct resulted in the discourses focussing on the practical issues related to compliance with the regulations. While the health technology discourse privileged security over privacy, all six discourses shared the understanding that privacy and security issues could be effectively managed through a combination of technology and policy measures. The issues and themes within each discourse determined the relative priority accorded technology or policy solutions.

8.2.1 Scholarly discourse

References to ‘data being stored in accordance with NHRMC requirements’ and ‘privacy requirements being maintained’ pointed to the acceptance of the privacy/public interest construct by the scholarly discourse. However the concepts were not frequently mentioned and were even less frequently the focus of discussion. Also absent from the discourse were discussions of the specific concepts (personal information, informed consent, de-identified data) or the privacy principles that underpin the operation of the privacy framework. Where privacy was discussed, the discussion focused on protecting privacy and ensuring access to information for legitimate purposes. Legitimate purposes included clinical and management applications. The discussion adopted a measured approach which sought to satisfy the needs of all stakeholders:

- The local GP may need to know all the test results but not the billing information, whereas a health insurance fund needs to know what tests were performed but not the results of the test, and researchers may want to access a profile of all tests results but should not have access to identifying information (Fitzpatrick, 1993)
- In healthcare there are many different social contexts. Each of these has their particular focus, views of the patient, ideals of health, and concepts of the health system (Southon & Cook, 2001)

With its focus on academic activity, research was the dominant focus for discussion in the scholarly discourse. When addressing research issues, the discourse acknowledged the need to protect privacy, but argued more strongly for access to personal information:

- Everyone has the responsibility to generate research questions and to make the best possible use of routinely collected data (Hovenga, 2001)
- A standardised electronic health record can provide new knowledge for health research (Croll & Croll, 2006)
- Privacy is a critical area that if not appropriately handled can have major consequences. For scientific epidemiological research it could be catastrophic (Croll & Croll, 2006)

The discourse acknowledged and conformed to privacy requirements for research, but criticised these requirements as restrictive:

- Ethics committees do not fully understand privacy legislation and generally oppose access to health information without consent (Croll & Croll, 2006,)
- Some compromise must be made between data quality/availability and privacy (Diment et al. 2009)

The criticism was justified by the claim that denying access to personal data limited research effectiveness. ‘There is evidence that over-protection of health data sources by primary users is preventing secondary access’ (Croll, 2008). This echoed a theme within the wider academic community. The National Health and Medical Research Council reported that it ‘was being told that the privacy framework surrounding health information in Australia was restricting health and medical research and health care delivery. These messages were coming from researchers, health consumers, medical practitioners, data custodians and human research ethics committees’ (2003, p. 5). Overall, the scholarly discourse presented a dualistic perspective, emphasising concerns about privacy and trust in the healthcare environment, while advocating more liberal access to the personal health information for research purposes.

8.2.2 Management discourse

The absence of any discussion about the privacy framework points to the management discourse accepting the parameters of the construct. Within these parameters, the discourse focused on meeting legislative and regulatory privacy requirements rather than the technical aspects of security. Yet references to privacy and confidentiality were limited. Many authors addressed privacy in just one or two sentences, often incorporating it as one of a number of issues:

- Key aspects of the project included patient need, relevance of activity, clinical relationship, logistics, privacy, cost, technology (Whiting & Hayes, 1999)
- Patient information should be timely, secure, private and confidential (Liaw, 1999)

Where discussions did occur, privacy and access to information were linked to the operational requirements of the health system. The discourse emphasised the need to prevent unauthorised use of personal health information but represented the pursuit of management goals as a legitimate secondary use of personal health information. This was justified as the means for achieving efficient and effective service delivery. The focus of these discussions was on consumer privacy 'ensuring that medical data are only available to a patient's authorised medical provider' (Crowe & McDonald, 1999), while issues of privacy in the context of monitoring the activities of health professionals were excluded. Yet a number of conference papers discussed projects involving increasing monitoring of health professionals. These papers pointed to an expansion of these practices over time. Early discussions emphasised use of de-identified data, while later discussions advocated use of identified data for monitoring, comparing and managing organisations, departments and individuals:

- The information on the INCIDE database does not identify individual patients, is not used to pinpoint individual clinicians or facilities (Lawson and Collopy, 1993)
- The CPR contains a suite of reports which allow Heads of Units to analyse performance in their own unit, Hospital Boards to analyse performance of their hospital and compare the relative performance of units within hospitals (Royle & Germann, 2006)
- Early applications of radio frequency identification technology such as infant tracking are now giving way to staff tracking, combined with time and motion studies to optimise work flows (Unnithan, Smith & Fraunholz, 2009)

Staff privacy was not highlighted as an issue in these discussions. Rather, increased surveillance of staff was justified in terms of achieving the organisation's goals. The management discourse acknowledged privacy for consumers while advocating expanded use of personal health information as legitimate practice in support of the goals of health care organisations.

8.2.3 Health Technology discourse

As with other discourses, discussion of privacy and security within the health technology discourse was limited. Where discussion did occur, security was privileged over privacy. Secure technical systems were represented as the key to meeting privacy requirements while maximising approved access to personal information and discussions focused on technical solutions to facilitate rather than restrict access to information

- Security issues need to be addressed – this must not rely on correct human behaviour (Patrick et al., 2006)
- Security can be managed through development of an ontology of privacy
- Implementing security policies ensures privacy and using security strategies obtains privacy (Liu et al. 2008)

The technology discourse used technical jargon, speaking of models and architectures, rule-based decision support systems and encryption to discuss programming issues related to establishing secure systems. This excluded non-technical discussions. Privacy was addressed in the context of developing technical systems to support ‘compliance with privacy regulations’ and meeting ‘privacy obligations’ rather than exploring questions of appropriate access to, or use of personal health information. Thus, a discussion about the implications of implementing an interoperability standard in the health care sector which had previously been adopted by the Federal Police, the Australian Taxation Office and Social Security focused on how this could be achieved, rather than on whether it was appropriate or ethical. At the same time, the discourse did mention, albeit fleetingly the issue of ethics: ‘matching patients can be difficult for technical, and ethical and legal reasons’.

8.2.4 Populations discourse

The populations discourse focused primarily on issues around the collection and use of large integrated, anonymous data sets with concerns primarily

expressed in terms of the ability of public health researchers, practitioners and policy developers to access these data repositories to enable them to perform their functions.

- Objectives are to promote the collection, compilation, analysis and dissemination of relevant, timely, accurate and reliable health information concerned the full range of health services and or a range of population parameters (Greville, 1993)
- A health knowledge base would be the hub for the planning, delivery and evaluation of care (Soar & Croll, 2001)
- A common requirement of applications on public health and biomedical research is the ability to link records in disparate databases (Pang & Hansen, 2006)
- As a nationally aggregated database, the NHMD is a high value information asset especially for research and funding organisation (Madsen, 2008)

The discourse emphasised the benefits of these activities, representing ‘information as a prerequisite for well-managed health care’, enabling ‘wide sharing of clinical research data to advance our knowledge of human disease’. A lack of access to aggregated data repositories was represented as ‘costly and inefficient’, ‘a major barrier to national change’, ‘resulting in subjective judgements’ and ‘expensive’. Although many of the activities discussed by this discourse utilised the de-identified or aggregated data that is outside the parameters of the privacy framework, privacy and security were stronger themes within this discourse than in most other discourses.

- Conclusions are based on comparisons. There is a need to access data relating to many individuals which may not always be de-identified (Walker, 1993)
- We need to find solutions that satisfy the rights of the individual but without restricting the abilities to research into health issues for the public good (Croll & Croll, 2006)
- Analyses of these health system usage and clinical data can yield information vital to effective health policy development and evaluation. The analyses of these health data archives must be conducted in such a way as not to compromise standards of privacy and confidentiality (O’Keefe, 2008)

- These records have the potential to be used in many ways across an integrated healthcare system (Boyle & Kong, 2009)

These statements point to the acceptance of the privacy/public interest construct, although some tension between privacy protection and the requirements for access to personal health information was evident: ‘The objective of sufficiently high data utility needs to be balanced against the objective of sufficiently low disclosure risk’ (O’Keefe, 2008). This manifested in some criticism of the legislation, but the argument was for expanded access for legitimated purposes rather than for increased privacy protection:

- Privacy is an emotive issue in this country. The result is that even for bona-fide research, access to any sort of personal health information is difficult (Kelman, 1999)
- Legislative, ethical and technical barriers make it exceedingly challenging for researchers to gain access to data (Kelman, 1999)

This discourse used the term surveillance when referring to routine collection of personal health information.

- Effective and efficient public health information management is facilitated through the rapid collation and analysis of surveillance data (Sintchenko et al., 2006)
- These databases typically have highly detailed clinical information including surveillance, familial and treatment subsets (Ross et al., 2006)
- Prospective biosurveillance for early detection of disease outbreaks (Akhtar et al. 2009)

This normalised both the concept and the activity, particularly where surveillance activities were discussed in terms of the benefits it brought to the community. As noted in surveillance literature, normalising the concept can make it difficult to question more intrusive forms of surveillance (Fuchs, 2011). The discourse also promoted the benefits of expanded uses for both personal information and de-identified data. Many individual papers described actual or proposed new uses of data from existing data repositories.

- Increasingly the data gathered from the health sector is being combined with data gathered for a range of other (non-health) sources in order to increase the value of the information that can be derived from it (Neame, 1993)
- It was decided to investigate just how useful this resource could be for a purpose for which it was not originally designed (Kelman, 1999)
- Recent developments in pathology message standardisation provide new opportunities for more effective and efficient public health information management through the rapid analysis of surveillance data (Sintchenko et al. 2006)

This established a context for function creep since these expanded uses were promoted as acceptable if they fell within the parameters of the privacy framework. Legislation can be amended to accommodate expanded uses.

8.2.5 Clinical informatics discourse

The clinical informatics discourse located privacy issues within the context of clinical care where professional practice and codes of ethical behaviour prioritise privacy and confidentiality. 'The threat to doctor-patient relationship and the loss of confidentiality is a very real concern for practitioners and patients alike' (Spinks & Cooper, 2001). This indicates the links between the clinical informatics discourse and professional discourses within medicine. Privacy and confidentiality are integral components of medical education. 'The five domains of general practice knowledge include 'communication skills, applied knowledge, population health, ethical and legal issues and organisational issues' (Tse & O'Shea, 2008). Unlike most other discourses, privacy and confidentiality, including consent mechanisms, were acknowledged as important in the clinical discourse. Discussions about the introduction of new programs, research activity or service delivery alluded to patient consent as a normal part of the process (Beischer, 2006; Barrett, 2008; Georgiou et al., 2009). The clinical discourse also considered privacy in terms of medico-legal obligations, focussing on the privacy of the clinician, and considering the extent to which information in computerised medical records is accessible or

admissible as evidence. It therefore emphasised the privacy requirements of the clinician:

- Another issue is that of the legality and therefore admissibility of computerised medical records (Cacek, 1993)
- Questions of consent relating to surgery have been raised in England since the 1960s and 1970s (Beischer, 2006)

The focus on the clinical environment where ethical professional practice governs behaviour marginalised discussion about function creep and other issues related to the broadening of legitimate access for secondary uses of personal health information. Such issues simply did not appear within this discourse. Consequently, the discourse emphasised strategies to restrict unauthorised access. Security was represented as the means for managing these issues.

- The system would aim for ‘moderate’ security as its purpose was to share information rather than conceal it (Parle & Lassere, 2008)
- Risk to privacy versus benefit of quality of care (Lassere et al., 2008)
- Issues relating to confidentiality of patient data are stated to be of major concern (Cacek, 1993)
- The EMR could enhance this with password protection, encryption, back-ups etc. (Parle & Lassere, 2008)

8.2.6 Nursing informatics discourse

Discussions of privacy and security were very limited within the nursing informatics discourse. The concepts were rarely mentioned. As with other discourses, reference to privacy was in general terms rather than identifying it as the focus of discussion. A typical comment was: ‘the advantages of networking include the ability to share files between work stations, the sharing of printers and security’ (Walker and Ford, 1993, p. 246). At the same time, the

discourse promoted the use of personal health information for improved clinical care and a range of management and governance purposes.

- Consideration should be given to other possible avenues or utilising systems, such as to improve information availability, work practice etc., to obtain optimal benefits for the investment (Chan, 2001)
- This data set could be claimed to be one of the most important developments to take place in community nursing because it ensures that community nursing services are both visible and accountable (Gliddon & Weaver, 1993)
- Objectives related to reviewing the flow of work to optimise the use of nursing resource to match patient care demands (McKechnie & Sangster, 1993)
- It is now possible to evaluate nursing practice and outcomes, and measure the effectiveness of program goals, to ensure the service provided is appropriate, effective and efficient (Anthony, 1993)

The nursing informatics discourse, as with other discourses, did not explore issues around the possible negative consequences of expanding legitimated uses of personal health information

8.3 Inclusions and exclusions

The limiting effect of statements leads to absences, and some possible interpretations that are not voiced or even thought of when the topic is approached from a particular viewpoint (Foucault, 1972, p. 86). Exclusions or absences from a discourse are therefore as significant as inclusions. Discussions about privacy, although not completely absent, were marginal in all six discourses. In the few papers where the concept was discussed it was, for the most part, addressed as a passing reference of one or two sentences. Of all papers included in the study, and across all the discourses, privacy was the focus of discussion in four papers. Security was the focus in two. This was indicated by titles of the papers:

- Privacy Impact Assessments – the Organisational versus the Individual’s viewpoints (Croll, 2008)

- Risk to Privacy versus Benefit of Quality Care: What Do Patients with Chronic Medical Conditions Choose (Lassere et al., 2008)
- EHR Privacy Risk Assessment Using Qualitative Methods (Madsen, 2008)
- Linking and Analysing Health Data with Appropriate Privacy and Security (Good et al., 2006)
- Security in PC Based Health Care Networks (Bennett & Bennett, 1993)
- Security as a Service – A Low Risk Approach to Integrating with NEHTA’s Security Specifications (Roadshaw, 2009)

This suggested that rather than being a significant issue within a discourse, privacy was a topic of interest at a particular time for individual authors who raised the issue but whose views remained marginalised. The acceptance of the privacy/public interest construct of the Australian privacy framework operated to marginalise privacy. This enabled the discourses to differentiate between decisions about what constituted appropriate use of health information, and the practical issues of managing access for legitimated uses of personal health information. The discourses located the former decisions outside the parameters of the discipline, and practical issues within it. Competencies developed by the Australian Health Informatics Education Council (2010) point to this. The competency ‘ethical and security issues including accountability of health care providers and managers and HI specialists and the confidentiality, privacy and security of patient data’ was ranked for the health informatics professional as level 3, ‘the ability to apply the knowledge’, rather than as a higher level competency requiring analytical or interpretative skills. This defined the role of health informatics professionals as ensuring compliance with the legislative framework rather than exploring issues relating to the operation of the framework. Concerns therefore focused on protecting individual privacy while facilitating access to personal health information for legitimated purposes, with the focus of each discourse determining what these legitimated purposes should be. Thus, the scholarly discourse included research as a legitimate purpose,

while the management discourse represented meeting management goals as legitimate.

Accepting the boundaries established by the privacy framework did not prevent challenges to the balance of privacy/public interest. The scholarly, populations, and management discourses challenged the balance although not in terms of appropriateness or consequences for individuals to whom the information related, but to argue for expanded access to personal data for health informatics and other health professionals. Justifications for this expanded use varied, reflecting the particular focus of each discourse. Within the scholarly discourse, academic research was considered a legitimate reason for expanding use of personal information. The management discourse argued that pursuit of management goals was an appropriate reason for changing the privacy/public interest balance. Within the public health discourse, expanded use of personal health information was justified in terms of the requirement for public health researchers, practitioners and policy developers to access the health data to enable them to perform their functions.

Missing from discussions in all discourses was a critique, or even acknowledgment, of function creep, particularly the occurrence of legal exceptions and other strategies that facilitated expanded uses of personal health information. Instead, the discourses shared an underlying acceptance that 'existing laws and practices cover the vast majority of legal issues' (Patterson, 2008). Yet existing laws and practices contribute, at least tangentially, contribute to the shaping of systems that facilitate function creep. The conference papers demonstrated this. Early texts emphasised privacy, confidentiality and the use of non-identifiable data. 'The information on the INCIDE database does not identify individual patients, is not used to pinpoint individual clinicians or facilities' (Lawson & Collopy, 1993 p.20). In later texts,

this emphasis changed with authors advocating the use of personal health information for an expanding range of secondary activities.

- The system provides a means of monitoring the assessment skills and care delivery of each practitioner as well as giving an effective method of review (Ford & Walker, 1993)
- The clinical reporting repository contains a suite of reports which allow Heads of Units to analyse the performance of their own unit and compare the relative performance of units within hospitals (Royle & Germann, 2006)
- A discussion of electronic tagging of hospital equipment included reference to a proposal to extend tagging to facilitate tracking of staff which could be combined with time and motion studies to optimise work flows (Unnithan, Smith & Frahholz, 2009)
- Tang-Taye and Turner discussed a proposal to expand a company-sponsored health and wellness trial program in which staff recorded health indicators and received feedback on their health status, to enable linking and cross-analysing of data on absenteeism and productivity to provide managerial insights into productivity (2009)

The activities described in these reports primarily from within the management discourse represent function creep. They describe situations in which information was collected and used for increasingly intrusive and controlling purposes.

8.4 Conclusion

The study found that all six discourses adopted the privacy/public interest dichotomy, strongly supporting expanded use of personal health information where the public interest could be established. The discourses were particularly supportive when proposed uses benefitted their discipline/discourse community. The discourses also shared the understanding that potential issues around the use of personal health information can be effectively managed through a combination of technology and policy measures. The implications of these findings are discussed in the final Chapter of the study.

Chapter 9: Discussion and conclusion

9.1. Introduction

This final chapter draws together the various strands of the study. It briefly revisits the context for the study before moving on to review the research questions, methodology and findings. These are discussed in terms of the theoretical and practical insights provided by the study. The discussion explicates the links between expanding systemic practices of information gathering, the role of the privacy framework in facilitating these practices and the academic discipline of health informatics as a key claim-making site for shaping this framework. The discussion reiterates the argument that power and influence shape personal health information management practices in Australia. It draws on the work of Michel Foucault to explain this as an integral element in the exercise of modern disciplinary power that produces docile, acquiescent and productive citizens. The chapter concludes by considering the contribution of the study and possible areas for further research arising from the findings.

9.1.1. Context for the study

The study posed the over-arching question '*Health Informatics: which piper, which tune, and who pays?*' with regard to the collection and use of personal health information in Australia. The purpose of the study was to explore the way the health informatics community supported or challenged these expanding uses of personal health information. The context for the study was the increasing use of personal health information for an expanding range of secondary purposes including service planning and evaluation, policy development, and health and medical research. While these secondary uses fall largely within the health care sector, they are increasingly expanding to non-health care organisations, including commercial organisations (Clarke, 2001; Greiner, 2005; Kruger, 2008; Phillips, 2003). A review of surveillance literature suggested that this expanding use of personal health information is not

occurring in isolation, but is symptomatic of a broader trend of expanding information gathering and surveillance practices being undertaken by contemporary governments and public and private sector organisations across the community. Surveillance studies highlight this trend while at the same time challenging the rationale, emanating primarily from political and economic communities, that expanding use of personal information is justified by widespread benefits and opportunities (Earl et al., 2009; Wood, 2006). Surveillance scholars argue that information gathering practices produce benefits and disadvantages that are not distributed equally and this has implications for inequality and discrimination (Lyon, 2001c; McCahill, 2007; Marx, 2005). A strong theme within surveillance literature is that many information gathering practices are moving beyond consensual monitoring processes to become increasingly focused on surveillance for managing and controlling citizens. This expansion from monitoring to surveillance is referred to as function creep (Ball and Wood, 2006; Clark, 1997; Johnston, 2006; Lyon, 2001; Marx, 2007). In Australia, analyses point to function creep occurring within the parameters of the privacy framework which is intended to oversee secondary use of personal information. These analyses suggest that the privacy framework, rather than being an objective, neutral mechanism, is a political process in which more powerful groups are able to shape decisions about what constitutes appropriate uses of personal information to enable them to pursue their own goals (Carter, 2000a; Clarke, 2003; Greenleaf, 2007a). Of particular interest are suggestions that function creep is a systemic practice embedded within the institutional and social practices of modern life (Australian Law Reform Commission, 2008b; Regan, 2007). It was in this context that the study sought to explore the way the health informatics community approached issues of access to and use of personal health information.

The health informatics community claims significant responsibility for both the academic discipline and the profession of health informatics. It contributes to

the production of the health informatics academic knowledge base, shapes the education and accreditation of health informatics professionals, and provides high-level expert advice to government health care organisations and other groups regarding laws, policies, strategies, systems and protocols governing the use of health information. Health informatics professionals are also integrally involved in the planning, implementation and oversight of the health information systems that facilitate the collection, manipulation and sharing of personal health information. This places the community in a position to influence both what should be done, and what can be done with personal health information. The way the community approaches the issues of personal health information use therefore has the potential to be very significant. To explore the influence of the community and its approach information management issues the study adopted a theoretical and methodological framework that linked the health informatics community, the Australian privacy framework and the broader systemic practices of expanding uses of personal health information discussed in the surveillance literature. Surveillance studies, with its comprehensive and informative description of expanding use of personal information for non-consensual surveillance provided the starting point for the study, while Foucault's work on the relationship between power, knowledge and discourse enabled the links between expanding use of personal health information, the privacy framework and the health informatics community to be explored.

Surveillance scholars represent expanding use of personal information as a systemic practice embedded within a network of institutional and social practices. However, as discussed in Chapter 2, surveillance studies focus on describing the processes and consequences of expanding uses of personal information rather than on explaining why it occurs. Michel Foucault also describes information gathering and surveillance practices as a network, but conceptualises this network as the exercise of modern disciplinary power. In

doing so, Foucault offered a framework for understanding the acquiescence of the community to expanding information gathering practices, explaining the interaction between power and knowledge as producing discourses, about social phenomena that ‘ensured the willing participation of citizens in the development of efficient economic systems’ (1980, p. 105). Foucault’s explanation therefore offered a structure for explaining both expanding use of personal information and the acquiescence of the community to these practices.

From a Foucauldian perspective, the Australian privacy framework forms part of the power/knowledge network that constructs discourses about the use of personal health information. Discourses are negotiated and defined within claim-making sites. Claim-making sites include education and research institutions, legal and government instrumentalities, government bodies, public and private health care and insurance organisations, the media and commercial organisations. The academic discipline of health informatics is one such claim-making site.

An academic discipline is a particularly powerful form of discourse, able to impose conformity about what knowledge is valid, how it is acquired, and how it is shared and used without recourse to external authorities (Lillis, 1997; Woodward-Kron, 1999). Health informatics thus represents an important site for shaping discourses about health information management. However, from a Foucauldian perspective, academic disciplines themselves comprise multiple discourses with the creation of disciplinary knowledge being a struggle between discourses seeking to assert their truth claims over others. Therefore, understanding the influence of the health informatics community in shaping understandings about the use of personal health information necessitated identifying the way dominant discourses within the health informatics community constructed these understandings.

9.2. The study methods and findings

The study was conducted in three phases. The first involved an analysis of the texts relating to the operation of privacy framework in Australia. The second phase of the study was the analysis of health informatics discourses with a particular focus on the way the discourses constructed issues relating to the use of personal health information. The third phase explored the relationships between the discourses. It identified the relative influence of the various discourses in shaping health informatics knowledge and practice. As discussed in Chapter 3, different texts or data, and different methods were used to achieve the goals of each phase of the study.

9.2.1 Effectiveness of the methodology

The study drew on the work of Michel Foucault to provide a theoretical framework. This framework pointed to discourse analysis as the most appropriate methodology. Chapter 3 identified different approaches to discourse analysis. Of these, Foucauldian discourse analysis and critical discourse analysis were considered. Both are concerned with interaction between language and the social world. Foucauldian discourse analyses seek to uncover the relationship between knowledge and power, while critical discourse analyses are frequently linked to policy analysis (van Dijk, 2001). Since the purpose of this study was to describe discourses and their interaction in the production of health informatics knowledge, a Foucauldian methodology was considered more appropriate. However, undertaking a Foucauldian analysis was not without challenges, the most significant of which was a lack of precise methodological principles. This allowed the criticism that that the selection of texts, the particular strategies used, and the particular discourses that emerge from an analysis are largely a matter of interpretation, and that others using the same theoretical framework and methodology, might find more, fewer or different discourses (Sharp & Richardson, 2001). These limitations were addressed by providing clear, specific descriptions about the methods and

strategies used for the analysis. It is argued that the limitations did not detract from the overall study and that the methodology was the most appropriate for the purpose of the analysis.

9.2.2 Analysing the privacy framework

The first phase of the study focussed on describing how issues around the use of personal information were constructed within the privacy framework. As discussed in Chapter 3, texts used for this included official documentation emanating from the formal monitoring, administering and evaluation processes of the privacy framework (legislation, educational material, reviews, reports, formal investigations), together with commentaries and critiques prepared by stakeholder groups and academic and professional communities. The documents were analysed to identify how the use of personal information was defined, and how this structured discussion. While this was a systematic and iterative process, it was a critical review of the literature rather than a Foucauldian discourse analysis.

The analysis confirmed that the Australian privacy framework approaches the use of personal information as an issue of individual privacy with privacy constructed as a relative right. Official documentation emphasised the legitimacy of both individual interests and other competing interests. Privacy was represented as paramount except in circumstances, where ‘public interest’, ‘public good’ and ‘public safety’ had priority. Much of the discussion revolved around interpretation of these and other concepts, many of which were broadly defined and/or circumscribed by exceptions that rendered them ambiguous and contestable. Official documentation depicted these ambiguities and the ensuing discussion as evidence of a healthy democratic process in which the efforts of different stakeholder groups to influence the operation of the framework is managed and controlled by neutral, objective umpires. Critics argued that the lack of clarity in defining concepts facilitated function creep. These

commentaries alluded to power differentials, pointing particularly to the ability of some stakeholders to influence or circumvent the privacy framework (Carter, 2000a; Clarke, 2003; Crompton, 2001; Greenleaf, 2007a; Versey, 2007). The critical commentaries echoed many of the issues discussed in surveillance literature. They pointed to increasing integration of personal health information into broader surveillance networks, noting that these networks create the opportunity for a move beyond consensual monitoring to non-consensual surveillance. As with surveillance literature, the implications of this trend were discussed in terms of the potential for discrimination and disadvantage. At the same time, critical commentaries did not challenge the private/public interest balance which underpins the privacy framework. Instead, as with surveillance studies, they focussed on practical issues and situations to do with implementation of the legislation, policies and protocols. Critical commentaries therefore contributed to the debate within managed parameters while at the same time reinforcing those parameters. Applying a Foucauldian explanation, the parameters govern the way that personal information management can be meaningfully thought of and spoken about, while limiting other ways in which the issue could be constructed. Within these parameters, acknowledged experts control the discussion because they are perceived to have knowledge that the wider population does not have. This claim to expert knowledge enables these groups to exercise power to shape the way information management issues are understood and to determine appropriate strategies to manage them. In doing so, these experts increase their legitimacy, whilst others are silenced and delegitimised. This first phase of the study provided the context for the analysis of health informatics discourses.

9.2.3 Health informatics discourses and privacy

From a Foucauldian perspective, the discipline of health informatics was considered a claim-making site where discourses about the use of personal health information are negotiated. However, Foucault argued that the academic

disciplines comprise multiple discourses that compete to shape disciplinary knowledge. This suggested that to explore the health informatics community as a claim-making site, it was first necessary to identify discourses and the interplay between them within the community. The starting point for this phase of the study were the research questions '*what discourses can be identified in the discipline of health informatics?*' and "*what is the relative influence of these discourses?*" The questions were addressed by describing discourses identified in the Health Informatics Society of Australia (HISA) national conference proceedings. An iterative analysis identified common themes, objects, concepts, and subject positions which determined what could and could not be discussed and who had the authority to participate in this discussion. The process is described in detail in Chapter 3. The relative influence of the discourses was determined by collecting evidence of communities of interest and institutional supports. For this aspect of the study, the conference texts were supplemented with official documentation from government, academic and other institutions, professional organisations, journals and other publications. These are listed in Appendix 1. Chapter 3 discusses the indicators of communities of interest in detail. They included the presence of:

- Institutionalised processes supporting the production and dissemination of disciplinary knowledge and practice
- Mechanisms to control health informatics skills and knowledge
- An identifiable system of status positions acknowledging health informatics expertise
- Organisations that promote the discipline and profession
- Mechanisms for dissemination of approved knowledge
- An identifiable active community of interest

In drawing on Foucault's theoretical arguments the study challenged the traditional historical narrative of health informatics knowledge development as continuous, cumulative and integrating. While the historical narrative

acknowledged the presence of different, even conflicting, views about the scope and issues of the field, they were explained as a characteristic of an emerging discipline which would be resolved as the discipline reached maturity (Coiera, 2006; Georgiou, 2002; McKenzie, 2000; Musen and van Bommel, 2003; Patel and Kauffman, 1998; Tolentino, 1999). However, this study supported Foucault's arguments, pointing to health informatics knowledge as comprising a fluctuating set of complementary and competing discourses rather than an internally consistent body of knowledge and practices. The study identified six discourses. These were the scholarly discourse, the nursing informatics discourse, the clinical informatics discourse, the populations discourse, the health technology discourse and the management discourse. Although a number of statements pointed to the adoption of a critical stance by some individuals in diverse locations at different times, no critical discourse was identified in this analysis. All six discourses shared the understanding that the discipline of health informatics is concerned with the collection, storage, manipulation and dissemination of health information. However, within this shared focus, discourses were differentiated according to the scope, focus and issues they delineated as being within the parameters of the discipline. The discourses were discussed extensively in Chapters 6 and 7. The discourses and their focus are summarised in Table 9.1

Table 9.1: Health informatics discourses identified in the study

Discourse	Scope, focus, issues
Scholarly discourse,	Discussed health informatics in terms of academic issues; The discourse emphasised effective resolution of health information management issues as best achieved through the accumulation of a formal body of knowledge to inform the practice of appropriately accredited health informatics professionals
Management discourse,	Discussed information and information management systems as supporting good management practices
Health technology discourse	Represented the discipline as primarily concerned with identifying and resolving the technical problems associated with the construction and implementation of clinical computer/information systems
Clinical informatics discourse	focused on the activities of clinicians in the immediate clinical environment

Nursing discourse	Spoke of health informatics in terms information management for nursing, practice
Populations discourse	Populations discourse was concerned with issues around the collection and use of aggregated data and information for service planning and implementation to proactively improve and maintain healthy population

While six discourses were clearly identifiable, the analysis suggested that the academic discipline was not neatly divided into discrete communities supporting particular discourses. Over the sixteen year period covered by the study the discourses interacted, competed, cooperated and colonised each other as they sought to control knowledge and knowledge production within the discipline. As discussed in Chapter 7, social processes and relationships supported particular discourses in different institutional sites. The relative influence of these sites, and the discourses they supported, changed over the period of the study. In 2006-2009, the scholarly, management and health technology discourses were clearly dominant. Each discourse was supported by identifiable communities of interest. These were located in different institutional sites. This was consistent with Foucault's representation of knowledge development as piecemeal, local and ad hoc, originating in localised communities in dispersed institutions.

The analysis suggested that by 2006-2009, the field of health informatics was gaining the status of an academic discipline with the scholarly, management, and health technology discourses increasingly able to control the production of knowledge, the education of new professionals and the oversight of health informatics professional practice. This regime of truth, or 'institutional infrastructure for the production and circulation of truth claims' (Introna, 2003, p 238), increased the legitimacy of the discipline's claims to expert knowledge and therefore its power to influence understandings about appropriate use of personal health information. The study therefore turned to the question *how do these discourses construct issues around use of personal health information?*

To explore this question, HISA conference texts were supplemented with the 2008 special edition of the *electronic Journal of Health Informatics*, which focussed on privacy and security issues. As discussed in Chapter 8, the study found that the discourses shared common understandings about privacy and the use of personal information. All six discourses accepted the parameters of the Australian privacy framework, constructing privacy as an individualistic, relative concept to be balanced against other rights and interests. When discussing this balance, the discourses generally expressed strong support for expanded use of personal health information where public interest had been established. Justifications for access to information for secondary uses reflected the particular focus of each discourse. These justifications were discussed extensively in Chapter 8, and are summarised in Table 9.2.

Table 9.2: Rationales for expanded use of personal health information

Discourse	Basis for support for expanded use of personal health information
Scholarly discourse,	Acknowledged the need to protect privacy, while arguing strongly for access to personal information for research purposes
Management discourse,	Pursuit of management goals was a legitimate reason for changing the privacy/public interest balance. Discussions focused on consumer privacy; use of personal information to monitor staff was justified in terms of achieving the organisation goals
Health technology discourse	Secure technical systems were represented as the key to meeting privacy requirements while maximising approved access to personal information; discussions focused on technical solutions to facilitate rather access to information rather than to restrict access
Clinical informatics discourse	Located privacy issues within the context of clinical care where professional practice and codes of ethical behaviour prioritise privacy and confidentiality
Nursing discourse	Located privacy issues within the context of clinical care where
Populations discourse	Argued for expanded access to both de-identified data and personal health information for public health research and policy development

Foucault argued that the limiting effect of statements in a discourse leads to absences, and some possible interpretations that are not voiced, or even thought of, when the topic is approached from a particular viewpoint (Foucault, 1972).

In this study, the texts emphasised practical issues around ensuring compliance with the legislation and minimising unauthorised access. Ethical issues about appropriate use of personal health information were largely absent. This is attributed to the way the discourses differentiated between decisions about appropriate use of health information and practical decisions relating to managing access for these legitimated uses. All six discourses constructed health informaticians as being primarily responsible for developing the practical mechanisms to manage access to personal health information for approved uses, while responsibility for determining what constituted appropriate uses was represented as outside the parameters of the discipline, and largely the domain of experts within regulatory and legislative bodies. This resulted in the discourses focussing on practical issues of compliance rather than on ethical issues around appropriate use of personal health information. The discourses therefore accepted the individual privacy/public interest balance determined by the domain experts within the regulatory and legislative bodies while implicitly accepting that potential issues arising from this balance could be effectively managed through a combination of policy and technology measures. This served to legitimise the discipline, whose rationale for existence is developing and managing electronic systems to facilitate use of personal health information. While the analysis identified some discussion about expanding use of personal health information and function creep in documentation from peak organisations, the issue was absent from conference papers and journal articles. This suggests that such discussion was largely absent from day-to-day deliberations. This focussed the study on the final question: *What might be the implications of this?*

The academic discipline of health informatics is strategically located to influence decisions about the use of personal health information in Australia. These decisions currently occur within the parameters established by the privacy framework which is based on the construct of personal information as a

privacy/public interest balance. This construct has been criticised as inadequate for managing function creep, a phenomenon argued to occur ‘at a systemic level (institutions, social practices, fabric of modern life), not at the level of private space’ (Regan, 2007, p. 497). The health informatics discourses adopted this privacy/public interest balance approach to information management, establishing parameters for discussion while limiting the capacity of the health informatics community to participate in debates about the privacy/public interest construct. Yet there is the opportunity for such a critique. Health informatics codes of ethics establish this. The International Medical Informatics Association code of ethics states that:

Health informatics professionals have a duty to ensure, to the best of their ability, that appropriate structures are in place to evaluate the technical, legal and ethical acceptability of the data-collection, storage, retrieval, processing, accessing, communication, and utilization of data in the settings in which they carry out their work or with which they are affiliated (IMIA, 2012).

This allows for some form of critique. The Australasian College of Health Informatics Code of Professional Conduct states that one of the fundamental duties of the health informatics professional is to respect the rights and the interests of patients and the public (ACHI, 2012, p. 1). While not explicit, this also allows for some form of critique. However, at the same time, the ACHI Code of Conduct states that:

Health informatics professionals should: ‘respect the rights and interests of others; carry out their duties with diligence and integrity for the benefit of key stakeholders and comply with any relevant legislation or regulations or technical standards, particularly those associated with protecting security confidentiality, accuracy and integrity of health information (2012, p. 2).

This reflects the positive, pluralistic, non-critical approach of the dominant discourses. It ignores the reality that to satisfy the rights and interests of some stakeholders may require the overriding of the rights and interests of other groups. It also overlooks the fact that in decisions about access to personal

health information, some stakeholders will have more power than others. While peak bodies of the health informatics community do comment on proposed expanding uses of personal health information, this study suggests that such a critique does not extend across the community where dominant discourses focus the discussion on practical issues of controlling legitimated access to personal health information. Consequently, issues around legal exceptions and other strategies that facilitate function creep are largely excluded from discussion. This raises the over-arching question of the study, *'Health Informatics: which piper, which tune, and who pays?'*

9.3 Which piper, which tune, who pays?

This study has argued that the legislation, policies and protocols that comprise the Australian privacy framework are not neutral or objective but are the result of political processes in which some stakeholders (pipers) have greater capacity to impose their understanding of the problem and solutions than do others. From a Foucauldian perspective, pipers are located within claim-making sites such as education and research institutions, legal and government instrumentalities, public and private sector organisations and the media. Within these claim-making sites, pipers compose tunes. In other words, they judge, negotiate and define the nature of problems and present them to the lay public accordingly (Hannigan, 1995). This study pointed to the health informatics community as a claim-making site that is increasingly shaping the production and dissemination of health informatics academic knowledge, overseeing the education and accreditation of health informatics professionals and contributing to high-level discussions regarding laws, policies, strategies, systems and protocols governing the use of health information. Health informatics academics and professionals, if not yet pipers, certainly help to keep the pipes polished. This raises the question *which tune?*

The Australian privacy framework is constructed on the understanding that the best approach to managing use of personal health information is by approaching it as a privacy/public interest balance. This is the tune (discourse), and it is very popular, dominating discussions around the use of personal health information both within claim-making sites and in the wider community. The privacy/public interest *tune* focuses on practical issues and situations to do with implementing the legislation, policies and protocols, highlighting the ways in which laws and other forms of regulation both enable and constrain the use of personal health information. It points to the ways in which political and institutional stakeholders seek to manipulate, modify or evade these regulations. This study pointed to the academic discipline of health informatics as playing this tune. Dominant discourses identified within the discipline broadly support the existing privacy framework, advocate the positive benefits of access to personal health information, and endeavour to develop the systems to facilitate this access. In doing so, the community manifests a relatively uncritical acceptance of rationales for expanding uses of personal health. This uncritical trust incorporates an implicit assumption that those determining appropriate and legal use of personal health information will get it right. This uncritical trust echoes what Manne (2011) refers to as ‘Australian smugness’, a ‘mood of national self-congratulation and self-satisfaction.’ Manne suggests that this attitude encourages an uncritical trust in authority. This uncritical trust may be argued to facilitate broad acceptance of the rationales for expanding uses of personal health information without a critical analysis of the implications of such uses. Clarke agrees, arguing that those who demonstrate complacency about the privacy-protective regime operating in Australia are out of touch with reality. ‘Complacency includes earnest discussions about microscopically unimportant details while massive flaws and gashes remain in the protective framework’ (Clarke, 1997). The lack of critique in the health informatics community may be a manifestation of this broader discourse operating across society to produce the docile, productive population that Foucault argued was

necessary for the functioning of modern societies. This brings up the final question: *who pays?*

As noted in the review of surveillance literature in Chapter 2, the most obvious targets for expanding monitoring and control are the already disadvantaged and marginalised (Ball & Wood, 2006; Clarke, 2006; Lyon, 2001a; Marx, 2007). Such groups, already largely ostracized, make justification about the common good, or community interest sound very plausible. Thus, the need to protect children and ensure welfare dollars were responsibly spent provided the rationale to justify monitoring families on welfare to ensure that children do their homework, are given ‘proper’ meals and go to bed at ‘a reasonable time’ (Little, 2009). It was not proposed to extend such monitoring to families not receiving welfare. Similarly, in Australia, the Federal Labor government proposed to link childhood immunisation to the Family Tax Benefit. Leake argues that, ‘children who already miss out by not being immunised may be further disadvantaged through economic disparities’ (cited in Sweet, 2011). Such programs may sound plausible but they are discriminatory, since they tend to affect only those families dependent on welfare. They are also coercive as families who do not conform may lose their social security benefits (Dunleavy, 2010; Leake, cited in Sweet, 2011). Families outside the gaze of the welfare system avoid such surveillance, although it can be argued that child neglect may also occur in these families. This supports the argument, both within surveillance literature and the privacy debate, that expanding surveillance can result in discrimination and disadvantage for some, often the most vulnerable, groups.

Yet it is not just the disadvantaged who pay. Ever-expanding routine monitoring and control of whole populations carries the potential for negative consequences for many individuals. This was noted in Chapter 2 with examples including genetic screening of all newborns in the United States, and proposed

mental health checks on all Australian three-year-olds (Butler, 2012; Mariner, 2007). Such programs are justified in terms of preventing illness or disability through early intervention, but carry the potential for labelling and discrimination of any child singled out for ‘treatment’.

Such obvious negative consequences are not the only cost of expanding use of personal information. More insidious consequences may reside in the expanding governance processes that are increasingly shaping the way people live their lives. These may be understood as the strategies of modern power described by Foucault. They include the imposition of more and more standards, performance indicators and targets, and the narrowing of the parameters considered ‘normal’ acting and thinking. Thus, in the public health arena, personal information is gathered and used to develop an expanding array of standards and guidelines, education and support programs and other strictures that are intended to ‘invest life through and through’ (Foucault, 1978, p. 139). Governance also increasingly structures the workplace where accreditation procedures, performance measures and quality standards proliferate. While represented as initiatives designed to improve clinical practice, raise the quality of care and provide efficiencies in service delivery, they also enable increased monitoring, measuring and control of the activities of health professionals (Gilbert, 2003; Gastaldo & Holmes, 1999; Ferlie et al 2012). As Foucault suggests, disciplinary power operates to increasingly control what we think and do. It appears that we all pay. However, Foucault also argued, there is always the possibility for resistance. It is possible to challenge the dominant discourses supporting these expanding governance practices.

9.4 Contribution of the study and further research

Applying Foucault’s ideas about the relationship between power, knowledge and discourses contributes to the discussion of the Australian privacy

framework. The study linked this framework to broader surveillance practices and power relationships on the one hand, and to the discipline of health informatics as an institutional claim-making site on the other. In doing so, the study challenged the accepted rationales for the collection and use of personal information, arguing that the practices of modern organisations are as much about the production of docile, self-regulating citizens as they are about the efficient management and improvement of goods and services. This moved the analysis beyond the discussions in the privacy literature where the focus is largely on practical issues around the implementation of the privacy framework. In this study, Foucault's conceptualisation of personal information and surveillance as elements of modern power allowed consideration of what appeared to be more innocuous uses of personal information. In doing so, the study pointed to the privacy framework as an instrument of modern disciplinary power. The study therefore suggests a need for more critical analyses of the expanding use of personal information, particularly the role of the privacy framework in supporting this expansion, to be undertaken. Alternative approaches to the privacy/public interest construct were noted in this study. These discussions, primarily located within surveillance literature, do question the individualistic privacy/public interest balance. While outside the parameters of this study, these alternatives warrant further discussion and research.

The study contributes to the discipline of surveillance studies, moving beyond the panoptic metaphor that has shaped much of the discussion in surveillance literature to incorporate a more comprehensive understanding of Foucault's work. This study linked the panoptic metaphor to Foucault's broader conceptualisation of modern power and its relationship to knowledge and discourse. It points to opportunities for increased application of this conceptualisation in surveillance research.

Finally, within the academic discipline of health informatics, the study provides a critical analysis of the links between the collection of personal health information and broader social practices and power relations in Australia. The study argues that to effectively contribute to discussions about the use of personal health information, the health informatics community needs to incorporate a critical perspective that will ‘identify and come to terms with inherent contradictions within the discipline and to take a stand on issues we often ignore – either unwittingly, but mostly wittingly’ (O’Donovan & Roode, 2002, p. 29).

9.5 Conclusion

The health informatics community has the option of continuing to participate in discussions within the parameters established by the privacy framework, or it may go beyond these parameters to challenge the dominant approach to personal health information management and, in doing so, address issues beyond a private trouble/public interest level. To adopt this form of critique would mean exploring alternative approaches to conceptualising information management issues. It would mean challenging the representation of the privacy framework as neutral. It would also mean identifying links between the collection of personal health information and broader social practices and power relations in Australia. Such a challenge would ‘invoke broader questions of social control and warn of the dangers of the creeping surveillance society’ (Bennett, 2011, p. 485). It would explain this creeping surveillance society in terms of disciplinary power and control not only of some individuals and groups but of the population as a whole.

The willingness to critique is increasingly imperative as the Australian Government progresses its plans for an Individual Health Identifier (IHI) and a Personally Controlled Electronic Health Record (PCEHR). As health information networks expand to intersect with other personal information networks, creating the potential for new, more widespread and more intrusive

forms of surveillance, it becomes even more imperative that the health informatics community participate in the critical debate.

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Appendix 1: Texts used in the discourse analysis

Conference texts

1993 Conference, Brisbane

Anthony, L 'Impact of Health Informatics Upon School Nursing Practice'

Ayrton, T 'Computerised Patient Information Systems – Their use in the emergency department and Total Quality Management'

Axford, R 'The Impact of Computerisation on Nursing Practice'

Bartley, E 'Ground Zero! Where Information Technology Meets Nursing Practice'

Egan, G O'Keefe, G O'Callaghan, D 'Computer Networking and Network Applications at the Austin Hospital Melbourne'

Bennett, J Glasziou, P 'A Review of the Usefulness of Advice and Therapy Systems in Clinical Medicine'

Bennett, J Bennett, D 'Security in PC Based Health Care Networks'

Botsman, K Smith, J 'A Drug Dosage Advisory System for Small Hospitals and Elsewhere'

Cacek, J 'Attitudes Toward Computerised Medical Records in General Practice'

Cater, B, Axford, R 'Computer Education for Nurse Practitioners – What should be taught?'

Chu, S Thom, J 'Nursing Informatics Towards the 21st Century'

Clarke, P Goddard, M 'A Structured Approach for Optimising the Laboratory Information Systems Implementation Project Lifecycle'

Cramond, S 'Health Care and the Internet: Research and practice information from world-wide networks in the 1990's'

Crowe, B De Silva, M Hailey, D 'Telemedicine Pilot Project at the Royal Alexandra Hospital for Children'

Egan, G O'Callaghan, D O'Keefe, G McKay, W Hennesy, O Fabinyi, G Morrison, I 'Medical Image Archive and Distribution System at the Austin Hospital'

Ellis, G 'Managing Large Databases on Complex Medical Knowledge Using Conceptual Graphs'

Fitzpatrick, G 'Business Process Redesign – Transforming Care Processes'

- Fitzpatrick, G 'Networked Systems Working for Care Providers'
- Ford, R Walker, B 'Computerised Innovation for Quality Aged Care'
- Foster, J Conrick, M 'Nursing Minimum Data Sets – A Comparison Between Countries'
- Gliddon, T Weaver, C 'The Community Nursing Minimum Data Set Australia Project: Real Life Issues of Operationalising a Common Data Set in Diverse Community Nursing Environments'
- Greville, T 'National Health Information Agreements'
- Hall, L 'Application of Classification and Coding in a General Practice Computerised Medical Record System'
- Hannan, T 'Inappropriate Variation-Quality, Waste-Quality Assurance: Mechanisms and Significance in Health Care'
- Hardie, D 'Data Management in Renal Transplantation: Information Technology and the Renal Transplant Unit at Princess Alexandra Hospital Brisbane'
- Hoare, J MacCallum, D 'Costs/Benefits of Imaging Medical Records'
- Hovenga, E Whymark, G 'Health Information Technology Standards – The need for an IT policy and strategy'
- Jayasuriya, R 'Computerizing Information Systems for Community Health in New South Wales: Current status and issues for future development'
- Johnson, J 'Pen Based Computing for Health Applications: Useful Technology When Appropriately Applied'
- Lange, A, Preparing Our Students for Future Health Informatics Developments'
- Lawson, M Collopy, P 'Australian Council on Healthcare Standards Care Evaluation Program'
- Leeder, T 'Strategic Planning for Nursing Information Technology at an Area Health Service Level'
- MacKenzie, G Rosenberger, S Schutz, S 'Lets Order Treatment – Not Trouble: Legal issues for implementing Order Entry'
- McKechnie, S Sangster, J 'Automated Systems in Support of Nursing'
- Mackie, P 'Managing the Investment in Health Information Systems: Art, Science or Guesswork?'

Moralee, M Della, P Dickinson, P, Successful Implementation of Information Technology in the Health Sector Depends on Nurses Attitude

Morris, D 'The Optical Memory Card as a Patient Health Obstetric Record – Report of the Queen Victoria Pilot Study'

Purcell, J 'Determining the Impact of Health Information Systems on Practice before Implementation'

Neame, R 'The Sorrento Model – An approach to integration and community orientation through Health Information Systems'

Shannon, B Hovenga, E 'The Identification of Data Sets Describing Nursing Practice in Australia'

Soar, J Bonderski, G 'The NSW Health IT Strategy – IT to support health care delivery'

Southon, F Yetton, P Burton, S 'Information Technology in a Hospital – A case study'

Thom, J Chu, S 'Has Anybody Seen My CIS? Why there is a lack of high quality point of care Clinical Information Systems in the Australian Environment'

Van der Weegan, L 'Order Entry by Doctors, A Myth or a Reality?'

Walker, B Ford, R 'Making IT Happen in Extended Care: The rewards and the pitfalls'

Walker, D "Fail Safe" Security

Walker, D 'Some Healthcare Terminology Browsers'

Walker, D "Finding the Needle" – Computer Searching Techniques Applied to MIMS Bi-Monthly and the Medicare Benefit Schedule (MBS) Books

Weaver, C 'Realising the Benefits from Information Technology: Applying New Wisdom to Quality Management Practices'

Wright, C 'What Really Happens in Clinical Conversations?'

Zelmer, A Baker, H 'Managing Technology Change: Barcode Technology in Health Systems'

1999 Conference, Hobart

Barrack, J Davis, S 'Clinical Pathways for All: A multidisciplinary approach to improving information management using Excelcare'

Blair, A Jensen, M Carder, R Mitchell C McNalty, E, 'Staff Stress Related To Computerised Patient Documentation in the Theatre Suite'

Blignault, I Snook, V 'Towards a national approach to telehealth evaluation: The work of the Australian New Zealand Telehealth Committee'

Damiani, S Brophy, J 'Supporting Seamless Patient Care and Business Intelligence'

Chan, C 'The Implementation of a Patient Care Information System'

Chee, K 'The Use of Web-based Clinical Knowledge as Decision Support Tool at the Point of Care'

Chu, S Wilkinson, J 'Building learner-centric self-directed, multi-media learning applications'

Cooper, H Davies, J Fernando, P Josephs, A 'Schattner, R, Dr Melbourne and Mr Hobart: two faces of telepsychiatry'

Crittenden, N Harper, J O'Shea, T Caputi, P Jayasuriya, R Rawstawne, P 'A validation of an information systems success model in a hospital setting using a qualitative and quantitative approach'

Crowe, B McDonald, I 'Evaluation of Development in Storage and Retrieval Systems for Health Information Systems'

Crow BL, McDonald IG 'Using technology to provide quality health care through improved service provision and continuing medical education: The example of Teleradiology in Australia'

Crowther, P Harnett, J 'Teaching Internet Technologies Using An Interactive Self Paced Approach'

Baily, G Bryant, J Fitzpatrick, G Kennedy, L Hayes, L Whiting, R 'The TARDIS Project'

Barrack, J Davis, S 'Clinical Pathways for All: A multidisciplinary approach to improving information management using Excelcare'

Dawson, S Davey, R 'The Ballarat and District Electronic Prescribing Mode'

Coiera, E Hardy, J Thorpe, M Jayasuriya, R Bannan, A 'Communication and Information Use for Improved Patient Care'

Douglas, E Hulcombe, J Ross, M 'Building a Partnership – Using Business Impact Analysis and Technical Review as a basis'

Kuang Onn, Y 'Docle coding and classification system browser'

Davies, F Pradhan, M 'Towards a core curriculum in Health Informatics – A survey and categorisation of core concepts from 12 Health Informatics courses'

- Fraser, C Brown, S 'The Littlefish Project: Open Source, Open Health'
- Ganguly, P Ray, P 'Internet-based Collaborative Work in Telehealth Systems'
- Gordon, J Crompton, J Bentley, C 'Clinical Outcomes and Information Systems – Bridging the Gap at the Coalface'
- Griswold, P 'A new theory with the introduction of the Electronic Patient Record: The importance of integrating knowledge, managerial, organisational and clinical cultures in the quest for success'
- Hage, M '“Black-box”-ology: An intern’s impression of e-topia'
- Harvey, P Morton, P Bissett, GP IT Networking and improved health outcomes in rural communities
- Harvey, K Geiselhart, K 'Health Policy and E-democracy – a new role for health informatics?'
- Heard, S Schloeffel, P Beale, T 'The Good Electronic Health Record'
- Ho, J Hovenga, E 'What do Health Care Workers have to say about Information Technology in their Workplace?'
- Hovel, J 'Teledermatology: Rural General Practitioner and Metropolitan Specialist Collaboration'
- Hovenga, E Tickle, K 'Is there a difference in attitudes towards computers and computer experiences between first year University students embarking on a career in health and other first year students?'
- Jahn, N 'Integrating Clinical and Management Data through a Real Time Operating Room Information System'
- Jane, E 'The Significance of People in Health Informatics'
- Keane, P Peterson, M 'New RAH/IMVS Library Service: towards a virtual library service: a case study'
- Kelman, C 'An investigation of the use of health administration data in the analysis of health outcomes: A model for the “post-market” surveillance of medical interventions'
- Laffey, J 'Electronic Commerce in the Australian Private health sector: The challenges and achievements'
- Liaw, S 'Online personal health management – why? will it work'
- Lugg, D 'Telemedicine: the cornerstone of Australian Antarctic medical practice'

McDonnell, R 'Data Warehousing with Smoke and Mirrors'

McDonnell, G 'Connecting the Health System: Why it is so hard and how the System bites back'

McPhee, W Bearman, M Cesnik, B 'A flexible approach to learning – the Graduate Certificate in Health Informatics'

Moo, S Sullivan, D 'A breakthrough in Community Care information management'

Mount, C 'Implementing an Integrated Health Record and Information System (IHRIS)'

Oliver, M Naidu, S Koronios, A McIntyre, Y Stalley, A 'A Multimedia-Based Clinical Decision Support System for Graduate Nurses Entering the Workforce'

Olszewski, C Cesnik, B Developing Middleware solutions – Recent experiences'

Pradhan, M and Farshid, G 'The use of Genetic Algorithms to optimise strategies for the detection in lymph nodes of metastatic spread'

Regan, B Regan, C 'Incorporating Digital Imaging into GP Education'

Scott, P Jersey, L 'IT – the servant of the clinician'

Swanson, B 'Telehealth and the law'

Thompson, H Jones, J Cruickshank, D 'Past Paper! Future Perfect?'

Toohy, M 'Quantifying the Impact of Iatrogenic Events on Inpatient Cost and Length Of Stay'

Walker, D Beilby, J Marley, J Chamberlain, N Duszynski, K Ravet, J Frank, O Henning, R Zaninovich, L Buckley, B Quay, E MacIsaac, P 'Facing the Future – Clinical Systems used for Epidemiological Research'

Weerakkody, G Ray, P 'Development of Information Systems with high QoS for Healthcare Environment'

Whiting, RW Hayes, LM Bryant, JT Fitzpatrick, G Bailey G Kennedy, L Hogg P 'TARDIS Project Report'

Williams, P 'Progress and Potential; Implementing Information Management in Health Care'

Wilson, L Brown, S Li, R 'Computer-based “expert assistance” for radiologists'

Woodcock, D Gillies, I 'The Electronic Medical Record as a Commodity Item'

Yellowlees, P 'Psychiatric Treatment – 2005_2010'

2001 Conference, Canberra

Bryant, G 'Data Accuracy – Commitment → Confidence'

Calabretto, J Warren, J Darzanos, K Fry, B 'Enhancing communication between patients and community pharmacists with an Internet Medicine Cabinet'

Chan, C, Moving with the Times: The New Handover – A Change of Practice'

Conrick, M Fraser, C Hulin, C 'The National Nursing Document Project'

Cook, R 'Quality information management in community based health services, a benefits led approach'

Crowe, B McDonald, I 'Using technology to provide quality health care through improved service provision and continuing medical education: The example of Teleradiology in Australia'

Dampney, C Pegler, G Johnson, M 'Harmonising Health Information Models – a critical analysis of current practice'

Davey, R Geddes, D 'Supporting eHealth Messaging Standards: Meeting the Challenge of Conformance Testing'

England I, 'The State of Health IT Expenditure: A Qualitative Study of Senior Executives in Regards to IT Investment'

Ganguly, P Nguyen, D Ray, P 'Semantic Interoperability of Healthcare Information Systems using Software Agent'

Hardy, J Drury, P Conn, C Ryan, K Communication Processes and Case Management Model of Care: Implications for IT development and implementation

Harvey, K Geiselhart, K 'Health Policy and E-democracy – a new role for health informatics?'

Hovenga, E 'Advancing Nursing Health Professional Cooperation to Improve Health Outcomes'

Innes, K Roberts, R Rust, J 'Raising the Flag: Coding for Safety and Quality in Health Care'

Kearsey, I Peasley, K Truran, D 'Comparison of results between a re-coding audit and analysis by PICQ'

Kitt, S Passalick, D Clayton, L Issues in developing models of linked communication in the Victorian Primary-Tertiary health care sector

Lederman, R Morrison, I 'The Cost of Data Delay – A Study Of The Impact Of Interrupted Data Flow On Patient Care And Hospital Queues'

Lewis, B 'Therapeutic Guideline development for integration with General Practice Information Systems.

McDonell, R 'Clinical Costing Kept Simple – The Case for Patient Activity Modelling'

McGill, A 'The Challenges for Health Informatics in Australia to 2005'

Murray, T Building and deploying a health industry Internet exchange: lessons learnt

Quain, D Davis, S Thompson, A 'Data accuracy and Excelcare: Are we expecting too much?'

Ray, P Cherian, B Vargas, B Mu 'Interoperability of Medical Information Systems using JAVA/CORBA with HL7'

Robinson, L Watson, K 'Closing the Gap between Best Practice Guidelines and Implementation – Collaboration is the Key'

Sintchenko, V 'Clinical decision support for antibiotic prescribing: Lessons learned from the mail and Web-based surveys of Australian physicians'

Soar, J Croll, P 'Data quality, e-Health and knowledge-management'
Southon G Cook, R 'Knowledge and Informatics: The Critical Role of Knowledge'

Spinks, K Cooper, J 'Results of a Study of Acceptance of Unique Patient Identifiers in a General Practice Setting'

Walters, C 'Meeting legislative requirements with an information system'

Westbrook, J Gosling, A 'Patterns of utilisation of the Clinical Information Access Program (CIAP) by clinicians in NSW: An analysis of web server logs'

Wollersheim, D 'A Review of Decision Support Formats with Respect to Therapeutic Guidelines Limited Requirements'

Yellowlees, P 'Consumers, customers, clients, patients and the web – an analysis of power and change'

2006 Conference Sydney

Ahamed, T Gogler, J Hullin, C Morrison, I, 'Nursing Decision Support 'Needs' for Better Patient Management'

Ashton, D 'A Practical Implementation of a Two Level Archetype Based Clinical Model'

- Beischer, A Cornoiu, A de Steiger, R Donnan, L Richardson, M 'The Use of Multimedia to Improve Patient Consent for Knee Arthroscopy'
- Boyle, J Karunanithi, M Chan, W Colavitti, C 'Benefits Realised by the EHRC Ambulatory Monitoring Project'
- Boyle, D Liaw, ST Morrison, I Cross, M 'Can Australian GPs Trust Their Software?'
- Brophy, J Edbrooke, A Eddy, A 'A Trial of Digital Pen Technology'
- Cacayan, B Davis, J Patrick, J Zhou, Y, 'Automated Ontology Mapping: A Multi-level Approach'
- Callen, JL Braithwaite, J Westbrook, JI 'Does the Clinical Environment Affect the Use of Computerised Physician Order Entry?'
- Chan, Z Croll, P Hansen, D Maeder, A 'The Use of Agent Technologies for Preserving Privacy with Health Records when Linking Federated Databases'
- Crollam, PR Croll, J 'Privacy Compliance - Managing the Risks when Integrating Health Data'
- Curry, J McGregor, C Tracy, S 'Incorporating Balanced Scorecards into the Patient Journey Modelling Process'
- Deray, K Simoff, SJ, 'A Model of Healthcare Interactions Based on Human Movement'
- Doran, CM; Sara, AF 'If It Is for Free, Is It Really Worth It?'
- Fernandes, L O'Connor, M, 'An Alternate to Unique Patient Identification: A Case Study of the Canada Patient Registry'
- Fry, B Warren, J, 'Supporting Multiple Navigation Paradigms in Internet-based Personal Healthcare Records'
- Garde, S Hovenga, E Granz, J Foozonkhah, S Heard, S 'Towards a Repository for Managing Archetypes for Electronic Health Records'
- Georgiou, A Westbrook, J McDonnell, G Magrabi, F 'Multi-method System Simulation Analysis as an Implementation and Evaluation Tool for Computerised Pathology Order Entry Systems'
- Gogler, J Hullin, C Mu, N 'Allergies and Alert Recording in a Tertiary Victorian Hospital: Paper and Electronic Health Records to Improve Patient Safety'
- Green, R Joyce, P, 'Systemic Issues of the Information System in the Healthcare Industry: Lessons Learned from the Field in Australia'
- Gu, Y Stanek, J Warren, J 'Knowledge Management (KM) Technologies in Medical Genetic Testing (MGT) Laboratories - a Literature Review'

Hancock, E Baker, A Degner, J 'Managing Resistance Constructively: Training Clinical Staff - Is It Like Herding Cats?'

Hansen, D 'Access to Distributed Data while Preserving Patient Privacy'

Ho, J Ribeiro, J Williams, S, 'Review of the Healthcare Client and Provider Identification Standards'

Johnson, CM Turley, JP, 'A New Approach to Building Web-based Interfaces for Healthcare Consumers'

Justin, L Hanson, R Fan, C Gehrig, M Dent, De Venables, P 'Costing Adverse Events by Linking Incident Monitoring and Clinical Costing Systems'

Leslie, H Heard, S 'Archetypes 101'

Lewis, B, 'An Electronic Clinical Audit Application for General Practice'

Lin, F 'The Role of Data Mining in Predictive Medicine: A Narrative Review'

Luanrattana, R, 'Strategies for Training Nurses to Work with Information Systems'

MacIsaac, P Clarke, P Legg, M Crowe, B Grimm, J, 'Applications of ICT to Diagnostic Imaging: A Review of Current Situation, Future Directions and Barriers to Achieving Them'

McCowan, I Moore, D Fry, MJ 'Automated Cancer Stage Classification from Free-text Histology Reports'

Madsen, M 'A Health Information Privacy Ontology: Toward Decision Support for Compliance Assessment'

Pang, C Hansen, D 'Improved Record Linkage for Encrypted Identifying Data'

Patrick, J Budd, P 'Automatic Conversion of Clinical Notes into SNOMED CT at Point of Care'

Patrick, J Ly, R Truran, D 'Evaluation of a Persistent Store for OpenEHR'

Patrick, J Wang, Y Miller, G O'Hallaran, J, 'Automatic Mapping ICPC2-PLUS Terms into SNOMED CT Terminologies'

Plummer, V 'Informing Nursing Resource Management - a Study of TrendCare Data'

Rochon, D Buck, DS Mahata, K Turley, JP 'The Evolution of Goal-negotiated Care'

Ross, B Ientile, J Hadzanovic, L Merriel, R Hibbert, M 'Information Based Medicine and the Molecular Medicine Informatics Model (MMIM) Project'

Royle, E Germann, S 'Careconnect.sa Datawarehouse Information for Improving Quality'

Sargent, J Eklund, P Ryan, A Burgess, L Cooper, J Alcock, C Ryan, D, 'Mobile Information Access and Diffusion in Ambulatory Care Service Settings'

Schloeffel, P Beale, T Hayworth, G Heard, S Leslie, H 'The Relationship between CEN 13606, HL7, and OpenEHR'

Schweikert, P Everett, P 'Towards a Better Patient Outcome'

Sheldon, AB Hodges, BR Doran, CM Sara, AF, 'Climbing the Escarpment'

Sintchenko, V Persson, L Lanser, J 'Communicable Disease Informatics - Emerging Concepts in Disease Surveillance'

Smith, M Harvey, R Abraham, N Hood, S Tannenbaum, D 'A Naturalistic Study of a Post-disaster Community Project Using Web-based Monitoring'

Thurston, LM 'Flexible and Extensible Display of Archetyped Data: The OpenEHR Presentation Challenge'

Tipper, S McDonnell, G 'Understanding the Dynamic Complexity of Medical Technology: A Systems Approach'

Tse, J Trumble, S, 'Information Mastery and Online Skills to Enhance Clinical Practice - a Study of General Practice Trainees'

Turner, P Wong, MC Yee, KC, 'Understanding Interactions of Factors Influencing Clinical Handover: Insights for Information Technology'

Whetton, S 'Health Informatics: Who Am I (and Does It Really Matter)?'

Williams, P Mahncke, RJ, 'Primary Care Information Security: A Case for Practical Assistance'

Wong, MC Yee, KC, 'Clinical Handovers: Two Sides of a Coin'

Yee, KC 'King Island Brie Model: The Role of Health Informatics in Medical Error Management'

2008 Conference, Melbourne

Alzougool, B Gray, K Chang, S 'Toward a Taxonomy of Information Needs of Informal Carers – A Case Study of a Carer of a Child with Diabetes'

Arnold, S Riches, V Parmenter, T Stancliffe, R 'The I-CAN: Using e-Health to Get People the Support They Need'

Bain, C Raikundalia, G Ratnayake, K 'OPDSS: A Strategic Management Information System for Hospital Outpatient Departments'

Balbo, S Gogler, J Steinkrug, J Lee, L Scheidt, S Hullin, C 'The Importance of Including Users in Clinical Software Evaluation: What Usability Can Offer in Home Monitoring'

Barrett, M Larson, A Carville, K Ellis, I 'The Expert Patient: The Key to Multi-Disciplinary Wound Care'

Bichel-Findlay, J Callen, J Sara, A 'An Information System's Contribution to Work Satisfaction: Differing Perspectives between Doctors and Nurses'

Boyle, J Lind, J Green, D Crilly, J Miller, P Wallis, M Jessup, M Fitzgerald, G 'Analysis of Patient Presentation and Admission Data for Prediction Modelling'

Browne, E 'Representing Clinical Concepts – HL7 RIM shortcomings impede information sharing'

Callen, J Paoloni, R Prgomet, M Georgiou, A Robertson, L Westbrook, J 'Can Information Technology Improve Test Result Follow-Up?'

Creswick, N Westbrook, J 'Social networks of staff in an emergency department'

Croll, P 'Privacy Impact Assessments – the Organisational versus the Individual's viewpoints'

Donnan, L Beischer, A Cornoiau, A De Steiger, R Graved, S Richardson, M 'Technology Mediated Learning in Healthcare: When a Picture Paints a Thousand Words'

Ferris, N MacIsaac, P McCauley, V Lindop, C Eichlberg, M Grimm, J 'Towards Delivery of Digital Diagnostic Imaging – Collaboration to Reach a Solution'

Forsyth, R Maddock, C Broadbent, M Iedema, R Lassere, M 'Patient Attitudes towards Improving Their Care by Carrying Their Own Medical Information: A Qualitative Analysis'

Fuchter, E Herlihy, R Shalloo, N 'Managing a State-wide eMR Clinical Transformation'

Georgiou, A Lam, M Westbrook, J 'Monitoring the Impact of CPOE on Healthcare Delivery – A Benefits Realisation Approach'

Gogler, J Hullin, C Monaghan, V Searle, C 'The Chaos in Primary Nursing Data: Good Information Reduces Risk'

Guest, G Green, R Bourke, J Lin, F Watters, D 'Mind the Gap: Minimising the Risk of Missing Pathology or Failing to Carry Out Planned Follow Up'

- Hansen, D Lawley, M Vickers, D Ryan-Brown, J Harrap, K O'Dwyer, M Melki, K McBride, S 'Accessing Patient Data for Chronic Disease Management'
- Jia, L Stranieri, A Shen, J 'An Intelligent Learning Environment for Traditional Chinese Medicine Practitioners and Students'
- Kelder, J Turner, P Lueg, C 'Supporting Community Knowledge Brokers: Information System Challenges in Breast Screening Service Delivery'
- Khambati, A Warren, J Grundy, J Hosking, J 'A Model Driven Approach to Care Planning Systems for Consumer Engagement in Chronic Disease Management'
- Lam, M Georgiou, A Westbrook, J 'Record Linkage – A Method to Generate an Enriched Dataset for the Student of CPOE Systems on Test Turnaround Time'
- Lassere, M Johnson, K Rappo, J Gellately, W Iedema, R Parle, A Rubin, G Sara, A Stelter, K 'Use of Patient-Held Paper-Based and Electronic-Based Portable Health Files (PHFs) To Facilitate Reliable Health Knowledge Transfer among Direct Health-Care Providers and Their Consumers-Patients: A Clinical Trial'
- Lassere, M Rappo, J Gellately, W Iedema, R 'Risk to Privacy versus Benefit of Quality Care: What Do Patients with Chronic Medical Conditions Choose'
- Le, Q Health Informatics in the Eyes of the Overseas-Born Health Professionals
- Lewis, N 'Health Informatics trends and issues – Telehealth'
- Liaw, S Boyle, D 'Secure Data Linkage and Information Sharing With GRHANITE'
- Madsen, M 'EHR Privacy Risk Assessment Using Qualitative Methods'
- Maeder, A 'Telehealth Standards Directions Supporting Better Patient Care'
- McDonald, T Hardy, J Kwok, C Lee, C 'Implementing Technology-Based Care and Management Systems for Effective Aged Care Outcomes: Issues and Recommendations'
- Nugrahanto, S Morrison, I 'A Design Science Approach to Modelling and Facilitating Clinical Workflow and Decision Making'
- Parle, A Lassere, M 'Engaging the Clinician: The Value of Rapid Prototyping of 'Lightweight' Electronic Health Records'
- Patterson, A 'A Case against Centralised Shared Electronic Health Records'
- Rushton, S Bichel-Findlay, J Ward, R Sinclair, S 'Using and It Platform to Deliver Standardised Cancer Information at The Point of Care'

Stanek, J Symon, B 'SNOMED-CT Coding in General Practice – Barriers and Opportunities'

Tse, J O'Shea, C 'Getting runs on the scoreboard – development of a formal health informatics curriculum statement for the RACGP'

Wade, V Izzo, J Hamlyn, J 'Videophone Delivery of Medication Management in Community Nursing'

Xie, J Burstein, F Evans, J 'Intelligent Support for Resource Quality Evaluation and Description in Health Information Portals'

2009 Conference

Akhtar, M Gallego, B Shiue, A Sintchenko, V 'Perspective Biosurveillance for Early Detection of Disease Outbreaks'

Besleaga, K Neill, D Kelly, J 'Identifying gaps in mental health services in a Local Government Area using GIS and data from clinical software'

Best, D 'Patient Home Monitoring with Telehealth Technologies in Queensland Health'

Bishop, J Bishop, A 'Looking Forward in Tracking Mental Illness'

Boyle, D Kong, F 'A systematic mechanism for the ethical collection and interpretation of display format pathology test results from Australian Primary Care records'

Brown, A Pittmann, M Baylie, U 'Multi System Interoperability using Internet based Technology and a Federated Architecture'

Buist, M 'An innovative information system to improve patient safety in the general ward environment – "Patientrack"'

Calabretto, J Lewis, B Reeve, J 'A preliminary investigation of an integration tool to improve access to information resources in clinical software'

Conley, C Wagnerien, B 'W-Fi Asset Tracking and Management for the Healthcare Enterprise.

Margelis, G, Providing Disease Management to the masses: What role for ICT?'

Cordwell, 'The ageing population, accessing services with the help of technology'

Counter, M 'Statewide Paperless Health Record for Queensland Sexual Health Clinics'

Diment, K Yu, P Garrety, K 'Complex Adaptive Systems as a Model for Evaluating Organisational Change Caused by the Introduction of Health Information Systems'

Dinh, D Dink, M Yee, K 'Alphastudy.com, bridging the healthcare knowledge gap and creating a faster route to knowledge dissemination'

Donaldson, P Sahama, T 'Identifying and using eHealth phobias to implement communication protocols and change cultural and social behaviours in eHealth'

Farrell, M Baldwin, I Weare, K 'Improving patient health outcomes in acute care hospital settings using mobile wireless technology and handheld computers'

Flabouris, A Nicholls, V 'Geospatial solutions for Critical Care Resource Evaluation and Planning'

Forsythe, J MacDonald, A Wilhelm, E Strachan, M Evans, D 'Efficacy of electronic discharge summaries: a case study demonstrating early results at two hospitals'

Garrett, J Stowasser, D Fahey, M O'Connor R, Clarke, L 'Extracting Existing Usage Data to Predict Future Requirements in Oncology and EMRs'

Georgeff, M Hilton, J 'The Use of CDMS for Collaborative Care (Wagner Chronic Core Model

Georgiou, A Westbrook, J Nicolarakis, P Hordern, A 'Medical service innovation in residential aged care – an evaluation of the HealthCube ICT-enabled comprehensive medical assessment service'

Grain, H Hovenga, E 'Challenges in health data – secondary data, modelling meaning'

Hafeez-Biag, A Gururajan, R 'Organizational, Technical & Perceived Readiness as Adoption Factors for Wireless Technology in Healthcare: An Australian Case Study'

Helal, M Sintchenko, V 'Dynamic programming algorithms for discovery of antibiotic resistance in microbial genomes'

Hicks, R 'Foundational Principles for Databases: Isolated or Interoperable (EHR)'

Hobson, C 'Economically Effective Health Information Management'

Hockings, C 'Imagine there's no passwords...'

Li, J Callen, J Georgiou, A Westbrook, J 'The challenges of using technology in a busy Emergency Department: a case study of a next generation ED management information system'

Lin, F 'Towards personalised pharmacotherapy: a perspective from biomedical informatics'

McBride, S Ryan-Brown, J Harrap, K 'Linked Data: First, low cost semantic interoperability for health care?'

- McLellan, S Galvin, M McMaugh, D ‘Benefits Measurement from the use of an Automated Anaesthetic Record Keeping System (AARK)’
- Margelis, G ‘Mobile Point of Care Solutions for improving Quality and Safety’
- Mok, M Osinski, M Barton, M Farrugia, H Giles, G, Chapman, A ‘Implementation of Population Based Clinical Cancer Data For Gynaecological Cancers’
- Nable, R Macdonald, P Edgecumbe, J ‘Widespread Uptake and Use of a Primary Care Data Tool by General Practices in Victoria’
- Naismith, P Pyefinch, F Kavanagh, J Stephenson, A ‘Implementation Experiences of the eRx Prescription Exchange’
- Nguyen, A Lawley, M Hansen, D Colquist, S ‘A Simple Pipeline Application for Identifying and Negating SNOMED Clinical Terminology in Free Text’
- O’Dwyer, M O’Dwyer, J Melki, K Crilly, J Lind, J Wallis, M Keijzers, G Tippet, V Peters, J Bost, N ‘Applied Data Linkage: from dirty data to clean complete patient records in Emergency Healthcare’
- Ranasinghe, I Sahama, T Yaralagadda, P ‘Evidence based healthcare planning in developing countries: An Informatics perspective’
- Ratnayake, A, Implementing eReferral and Service Coordination in the Health and Community Sector from the bottom up’
- Readshaw, N ‘Security as a Service – A Low Risk Approach to Integrating with NEHTA’s Security Specifications’
- Richman, R Chan, L Whiteley, J Roberts, A Lippiatt, D Farrell, P ‘No longer Lost in Translation’
- Richman, R Cullen, J Laurens, J Tsaprounis, G Segaert, N Bourke, R,’ High Returns Pharming COWs’
- Ryan, A Ekland, P ‘Ontology Mapping between HL7 Versions 2 and 3 and OpenEHR for Observations Messages’
- Sahama, T ‘Health Informatics Domain Knowledge Analysis: An Information Technology Perspective’
- Sayer, G Whicker, S Marshall, P ‘Use of Electronic Patient Management Systems and the Impact of Drug Interaction Warnings: the General Practice Research Network’
- Scott, P McIntyre, A Davison, J Tattam, P ‘Use of GELLO v.1, GLIF 3.5, SNOMED-CT and EN13606 archetypes’

Soar, J Wang, Z 'Information for guided chronic disease self-management in community settings'

Steele, C Connors, T Smolenaers, F 'The Impact of Rapid Roaming User Access on Workforce Efficiency in Aged Care'

Stevens, G 'Mirrijini Dispense System (MDS) Managing Medicines in remote Aboriginal Clinics'

Stevens, G 'Prompting and monitoring patient compliance using SMS Medication Support System'

Stevens, G 'eWebstercare online ordering and communication system'

Tang-Taye, J Turner, A 'Is a Health and Wellness program based on Telehealth profitable in a workplace environment? A managerial approach'

Thomas, D 'Paper-based or paperless? Challenges and Realities of removing paper from the Medical Record'

Truran, D Saad, P Zhang, M Innes, K Innes, K Kemp, M Huckson, S Bennett, S 'Using SNOMED CT – enabled data collections in a national clinical research program; primary care data can be used in secondary studies'

Tsafnat, G Sanden, L Kaeseler, N 'New Decision Support Paradigm for Bioinformatics in Antibiotics Prescription Support Systems'

Unnithan, C Smith, R Fraunholz, B 'Maximising the Benefits of Radio Frequency Identification Technology (RFID) Integration in Clinical Contexts: a Linear Conduit'

Vickers, D Lawley, M 'Mapping existing medical terminologies to SNOMED CT: An investigation of the novice user's experience'

Wong, YK 'A Model for HealthCare System Quality'

Electronic Journal of Health Informatics

Vol 3, No 1 (2008): Special Issue on Privacy and Security

Croll, P 'Editorial'

Bracher, S & Krishnan, P 'Secure Document Circulation: An Architecture for e-Health'

Caffery, L Stathis, S Smith, A 'An Encrypted Email Application for Paediatric and Adolescent Mental Health Teleconsultations'

de la Motte, L Hartnett, J 'Using a Client-Task Based Approach to Achieve a Privacy Compliant Access Control System'

Fernando, J Dawson, L 'Clinician assessments of workplace security training- an informatics perspective'

Jøsang A 'Online Reputation Systems for the Health Sector'

Li, J Wang, H Jin, H Yong, J 'Current Developments of k-Anonymous Data Releasing'

Liu, V May, L Caelli, W Croll, P 'Strengthening Legal Compliance for Privacy in Electronic Health Information Systems: A Review and Analysis'

O'Keefe, C 'Privacy and the Use of Health Data - Reducing Disclosure Risk'

Health Informatics Society of Australia

http://www.hisa.org.au/?page=hisa_resources

2005 HISA Constitution

2006 Annual Report Presentation

2006 HISA Final Accounts

2006 Member Survey Analysis

2007 Submission on Privacy in Health Information Presented to the Australian Law Reform Commission

2007 Membership Survey

2007 Submission to the Boston Consulting Group NEHTA Review

2007 A Vision for an Australian Healthcare System Transformed by Health Informatics

2007 A Vision for an Australian Healthcare System Transformed by Health Informatics

2008 AHHA National Health Policy Roundtable Discussion Paper: Information Management

2008 DH4 Summary of E-Health and Health Information Measures

2008 HISA Prebudget Submission

2008 Submission on Privacy in Health Information presented to the Australian Law Reform Commission

2008 Report eJHI

2009 CeH Letter to PM: Fast-tracking health reform through e-health

2009 A Review of the Australian Health Informatics Workforce

Australasian College of Health Informatics

2005 ACHI Paper on eHealth Strategy

2006 ACHI Submission on Access Card Privacy

2006 Australian Health Informatics Educational Framework

2007 Report on NEHTA and ACSQH e-Health Conference

2007 ACHI Submission to NEHTA Review

2007 ACHI Panel Presentation on Success Factors Review

2007 National eHealth Health strategies: A review of success factors in 5 countries

2008 ACHI Submission to the National Health and Hospitals Reform Commission

2009 ACHI Response to NEHTA Draft "Electronic Transfer of Prescription"

2009 ACHI Response to AHMAC Discussion Paper on "Health Identifiers & Privacy"

2009 Australian Health Informatics Education Council 'Work Plan 2009-10 and Beyond'

2010 ACHI Submission to Senate Enquiry into the Health Identifier

2010 ACHI Response to Draft Health Identifier Legislation

2011 Response to DoHA "PCEHR Legislative Issues"

2012 ACHI Professional Code of Conduct

Appendix 2: Discourses dominant in conference papers

Changes in the presence of the discourses in conference papers

Discourse	1993	1999-2001	2006-2009	
Clinical	5	11	33	49
Health Technology	10	17	41	68
Management	16	32	25	73
Nursing	11	6	5	22
Populations	3	5	16	24
Scholarly	6	20	23	49
Total	51	91	143	285

1993 Conference, Brisbane

Clinical

Bennett, J Glasziou, P 'A Review of the Usefulness of Advice and Therapy Systems in Clinical Medicine'

Cacek, J 'Attitudes Toward Computerised Medical Records in General Practice'

MacKenzie, G Rosenberger, S Schutz, S 'Lets Order Treatment – Not Trouble: Legal issues for implementing Order Entry' *

Thom, J Chu, S 'Has Anybody Seen My CIS? Why there is a lack of high quality point of care Clinical Information Systems in the Australian Environment'

Van der Weegan, L 'Order Entry by Doctors, A Myth or a Reality?'

Health Technology

Botsman, K Smith, J 'A Drug Dosage Advisory System for Small Hospitals and Elsewhere'

Cramond, S 'Health Care and the Internet: Research and practice information from world-wide networks in the 1990's'

Egan, G O'Callaghan, D O'Keefe, G McKay, W Hennesy, O Fabinyi, G Morrison, I 'Medical Image Archive and Distribution System at the Austin Hospital'

Ellis, G 'Managing Large Databases on Complex Medical Knowledge Using Conceptual Graphs'

Hall, L 'Application of Classification and Coding in a General Practice Computerised Medical Record System'

Johnson, J 'Pen Based Computing for Health Applications: Useful Technology When Appropriately Applied'

Morris, D 'The Optical Memory Card as a Patient Health Obstetric Record – Report of the Queen Victoria Pilot Study'

Walker, D "Finding the Needle" – Computer Searching Techniques Applied to MIMS Bi-Monthly and the Medicare Benefit Schedule (MBS) Books

Walker, D 'Some Healthcare Terminology Browsers'

Wright, C 'What Really Happens in Clinical Conversations?'

Management

Ayrton, T 'Computerised Patient Information Systems – Their use in the emergency department and Total Quality Management'

Bennett, J Bennett, D 'Security in PC Based Health Care Networks'

Clarke, P Goddard, M 'A Structured Approach for Optimising the Laboratory Information Systems Implementation Project Lifecycle'

Crowe, B De Silva, M Hailey, D 'Telemedicine Pilot Project at the Royal Alexandra Hospital for Children – Evaluation Aspects'

Egan, G O'Keefe, G O'Callaghan, D 'Computer Networking and Network Applications at the Austin Hospital Melbourne'

Fitzpatrick, G 'Business Process Redesign – Transforming Care Processes'

Ford, R Walker, B 'Computerised Innovation for Quality Aged Care'

Hannan, T 'Inappropriate Variation-Quality, Waste-Quality Assurance: Mechanisms and Significance in Health Care'

Hardie, D 'Data Management in Renal Transplantation: Information Technology and the Renal Transplant Unit at Princess Alexandra Hospital Brisbane'

Hoare, J MacCallum, D 'Costs/Benefits of Imaging Medical Records'

Jayasuriya, R 'Computerizing Information Systems for Community Health in New South Wales: Current status and issues for future development'

Lawson, M Collopy, P 'Australian Council on Healthcare Standards Care Evaluation Program'

Mackie, P 'Managing the Investment in Health Information Systems: Art, Science or Guesswork?'

Purcell, J 'Determining the Impact of Health Information Systems on Practice before Implementation'

Soar, J Bonderski, G 'The NSW Health IT Strategy – IT to support health care delivery'

Weaver, C 'Realising the Benefits from Information Technology: Applying New Wisdom to Quality Management Practices'

Zelmer, A Baker, H 'Managing Technology Change: Barcode Technology in Health Systems'

Nursing

Anthony, L 'Impact of Health Informatics Upon School Nursing Practice'

Axford, R 'The Impact of Computerisation on Nursing Practice'

Bartley, E 'Ground Zero! Where Information Technology Meets Nursing Practice'

Carter, B, Axford, R 'Computer Education for Nurse Practitioners – What should be taught?'

Chu, S Thom, J 'Nursing Informatics Towards the 21st Century'

Foster, J Conrick, M 'Nursing Minimum Data Sets – A Comparison Between Countries'

Gliddon, T Weaver, C 'The Community Nursing Minimum Data Set Australia Project: Real Life Issues of Operationalising a Common Data Set in Diverse Community Nursing Environments'

Leeder, T 'Strategic Planning for Nursing Information Technology at an Area Health Service Level'

McKechnie, S Sangster, J 'Automated Systems in Support of Nursing'

Moralee, M Della, P Dickinson, P, Successful Implementation of Information Technology in the Health Sector Depends on Nurses Attitude

Shannon, B Hovenga, E 'The Identification of Data Sets Describing Nursing Practice in Australia'

Walker, B Ford, R 'Making IT Happen in Extended Care: The rewards and the pitfalls'

Populations

Greville, T 'National Health Information Agreements'

Neame, R 'The Sorrento Model – An approach to integration and community orientation through Health Information Systems'

Walker, D "Fail Safe" Security

Scholarly

Brittain, M 'Managing the benefits of IT in healthcare – human resources'

Fitzpatrick, G 'Networked Systems Working for Care Providers'

Hovenga, E 'Foreword to Conference Proceedings'

Hovenga, E Whymark, G 'Health Information Technology Standards – The need for an IT policy and strategy'

Lange, A, Preparing Our Students for Future Health Informatics Developments'

Southon, F Yetton, P Burton, S 'Information Technology in a Hospital – A case study'

1999-2001

Clinical

Baily, G Bryant, J Fitzpatrick, G Kennedy, L Hayes, L Whiting, R 'The TARDIS Project'

Calabretto, J Warren, J Darzanos, K Fry, B 'Enhancing communication between patients and community pharmacists with an Internet Medicine Cabinet'

Cooper, H Davies, J Fernando, P Josephs, A Schattner, R, 'Dr Melbourne and Mr Hobart: two faces of telepsychiatry'

Crow BL, McDonald IG 'Using technology to provide quality health care through improved service provision and continuing medical education: The example of Teleradiology in Australia'

Dawson, S Davey, R 'The Ballarat and District Electronic Prescribing Mode'

Hage, M 'Black-box'-ology: An intern's impression of e-topia'

Pradhan, M and Farshid, G 'The use of Genetic Algorithms to optimise strategies for the detection in lymph nodes of metastatic spread'

Scott, P Jersey, L 'IT – the servant of the clinician'

Sintchenko, V 'Clinical decision support for antibiotic prescribing: Lessons learned from the mail and Web-based surveys of Australian physicians'

Whiting, RW Hayes, LM Bryant, JT Fitzpatrick, G Bailey G Kennedy, L Hogg P 'TARDIS Project Report'

Wilson, L Brown, S Li, R 'Computer-based "expert assistance" for radiologists'

Health Technology

Chee, K 'The Use of Web-based Clinical Knowledge as Decision Support Tool at the Point of Care'

Chu, S Fraser, C Hulin, C 'Developing standard documentation templates and information models'

Dampney, C Pegler, G Johnson, M 'Harmonising Health Information Models – a critical analysis of current practice'

Davey, R Geddes, D 'Supporting eHealth Messaging Standards: Meeting the Challenge of Conformance Testing'

Fraser, C Brown, S 'The Littlefish Project: Open Source, Open Health'

Heard, S Schloeffel, P Beale, T 'The Good Electronic Health Record'

Ganguly, P Ray, P 'Internet-based Collaborative Work in Telehealth Systems'

Ganguly, P Nguyen, D Ray, P 'Semantic Interoperability of Healthcare Information Systems using Software Agent'

Lugg, D 'Telemedicine: the cornerstone of Australian Antarctic medical practice'

McDonnell, G 'Connecting the Health System: Why it is so hard and how the System bites back'

McDonell, R 'Clinical Costing Kept Simple – The Case for Patient Activity Modelling'

Mount, C 'Implementing an Integrated Health Record and Information System (IHRIS)'

Oon, KY 'Docle coding and classification system browser'

Pradhan, M Crichton, T Edmonds, M and Ludbrook, G 'A comparison with statistical models of an evidence-based decision support system for the prophylaxis of post-operative nausea and vomiting'

Pradeep, R Cherian, B Vargas, B Mu 'Interoperability of Medical Information Systems using JAVA/CORBA with HL7'

Wollersheim, D 'A Review of Decision Support Formats with Respect to Therapeutic Guidelines Limited Requirements'

Woodcock, D Gillies, I 'The Electronic Medical Record as a Commodity Item'

Management

Barrack, J Davis, S 'Clinical Pathways for All: A multidisciplinary approach to improving information management using Excelcare'

Blignault, I Snook, V 'Towards a national approach to telehealth evaluation: The work of the Australian New Zealand Telehealth Committee'

Bryant, G 'Data Accuracy – Commitment → Confidence'

Chan, C 'The Implementation of a Patient Care Information System'

Cook, R 'Quality information management in community based health services, a benefits led approach'

Crowe, B McDonald, I 'Using technology to provide quality health care through improved service provision and continuing medical education: The example of Teleradiology in Australia'

Damiani, S Brophy, J 'Supporting Seamless Patient Care and Business Intelligence'

Douglas, E Hulcombe, J Ross, M 'Building a Partnership – Using Business Impact Analysis and Technical Review as a basis'

Gordon, J Crompton, J Bentley, C 'Clinical Outcomes and Information Systems – Bridging the Gap at the Coalface'

Harvey, P Morton, P Bissett, 'GP IT Networking and improved health outcomes in rural communities'

Jahn, N 'Integrating Clinical and Management Data through a Real Time Operating Room Information System'

Keane, P Peterson, M 'New RAH/IMVS Library Service: towards a virtual library service: a case study'

Kitt, S Passalick, D Clayton, L Issues in developing models of linked communication in the Victorian Primary-Tertiary health care sector

Laffey, J 'Electronic Commerce in the Australian Private health sector: The challenges and achievements'

Liaw, S 'Online personal health management – why? will it work'

McDonnell, R A 'Clinical Costing – In-house versus Outhouse'

McDonnell, G 'Connecting the Health System: Why it is so hard and how the System bites back'

McDonnell, R 'Data Warehousing with Smoke and Mirrors'

McGill, A 'The Challenges for Health Informatics in Australia to 2005'

Moo, S Sullivan, D 'A breakthrough in Community Care information management'

Murray, T Building and deploying a health industry Internet exchange: lessons learnt

Olszewski, C Cesnik, B 'Developing Middleware solutions – Recent experiences'

Quain, D Davis, S Thompson, A 'Data accuracy and Excelcare: Are we expecting too much?'

Robinson, L Watson, K 'Closing the Gap between Best Practice Guidelines and Implementation – Collaboration is the Key'

Swanson, B 'Telehealth and the law'

Thompson, H Jones, J Cruickshank, D 'Past Paper! Future Perfect?'

Toohey, M 'Quantifying the Impact of Iatrogenic Events on Inpatient Cost and Length Of Stay'

Walters, C 'Meeting legislative requirements with an information system'

Whiting, RW Hayes, LM 'The Partnership Project – An Overview: A National Demonstration Environment for the Evaluation and Implementation of Health Informatics' *

Williams, P 'Progress and Potential; Implementing Information Management in Health Care'

Wilson, LS Sharp, IF Gill, RW Heitman, SA Chen, CF Dadd, MJ Kajan, A Gunaratnam, M and Tam, E 'The Hospital Without Walls – home telecare using vital signs monitoring'

Yellowlees, 'Psychiatric Treatment – 2005_2010'

Nursing

Blair, A Jensen, M Carder, R Mitchell C McNalty, E, 'Staff Stress Related To Computerised Patient Documentation in the Theatre Suite'

Chan, C, Moving with the Times: The New Handover – A Change of Practice'

Conrick, M Fraser, C Hulin, C 'The National Nursing Document Project'

Ho, J Hovenga, E 'What do Health Care Workers have to say about Information Technology in their Workplace?'

Hovenga, E Tickle, K 'Is there a difference in attitudes towards computers and computer experiences between first year University students embarking on a career in health and other first year students?'

Oliver, M Naidu, S Koronios, A McIntyre, Y Stalley, A 'A Multimedia-Based Clinical Decision Support System for Graduate Nurses Entering the Workforce'

Populations

Kelman, C 'An investigation of the use of health administration data in the analysis of health outcomes: A model for the "post-market" surveillance of medical interventions'

Walker, D Beilby, J Marley, J Chamberlain, N Duszynski, K Ravet, J Frank, O Henning, R Zaninovich, L Buckley, B Quay, E MacIsaac, P 'Facing the Future – Clinical Systems used for Epidemiological Research'

Soar, J Croll, P 'Data quality, e-Health and knowledge-management'

Southon G Cook, R 'Knowledge and Informatics: The Critical Role of Knowledge'

Innes, K Roberts, R Rust, J 'Raising the Flag: Coding for Safety and Quality in Health Care'

Scholarly

Austin, D Szeto, H Fitzpatrick, G Wyeth, P 'Understanding community health care: Implications for technology design;

Chu, S Wilkinson, J 'Building learner-centric self-directed, multi-media learning applications'

Crittenden, N Harper, J O'Shea, T Caputi, P Jayasuriya, R Rawstawne, P 'A validation of an information systems success model in a hospital setting using a qualitative and quantitative approach'

Davies, F Pradhan, M 'Towards a core curriculum in Health Informatics – A survey and categorisation of core concepts from 12 Health Informatics courses'

England I, 'The Statue of Health IT Expenditure: A Qualitative Study of Senior Executives in Regards to IT Investment'

Griswold, P 'A new theory with the introduction of the Electronic Patient Record: The importance of integrating knowledge, managerial, organisational and clinical cultures in the quest for success'

Hardy, J Drury, P Conn, C Ryan, K Communication Processes and Case Management Model of Care: Implications for IT development and implementation

Harvey, K Geiselhart, K 'Health Policy and E-democracy – a new role for health informatics?'

Hovel, J 'Teledermatology: Rural General Practitioner and Metropolitan Specialist Collaboration'

Hovenga, E 'Advancing Nursing Health Professional Cooperation to Improve Health Outcomes'

Jane, E 'The Significance of People in Health Informatics'

Lederman, R Morrison, I 'The Cost of Data Delay – A Study Of The Impact Of Interrupted Data Flow On Patient Care And Hospital Queues'

Lewis, B 'Therapeutic Guideline development for integration with General Practice Information Systems.

McPhee, W Bearman, M Cesnik, B 'A flexible approach to learning – the Graduate Certificate in Health Informatics'

Crowe, B McDonald, I 'Evaluation of Development in Storage and Retrieval Systems for Health Information Systems'

Southon, G Cook, R 'Knowledge and Informatics: The Critical Role of Knowledge'

Spinks, K Cooper, J 'Results of a Study of Acceptance of Unique Patient Identifiers in a General Practice Setting'

Weerakkody, G Ray, P 'Development of Information Systems with high QoS for Healthcare Environment'

Westbrook, J Gosling, S 'Patterns of utilisation of the Clinical Information Access Program (CIAP) by clinicians in NSW: An analysis of web server logs

Yellowlees, P 'Consumers, customers, clients, patients and the web – an analysis of power and change'

2006-2009

Clinical

Balbo, S Gogler, J Steinkrug, J Lee, L Scheidt, S Hullin, C 'The Importance of Including Users in Clinical Software Evaluation: What Usability Can Offer in Home Monitoring'

Barrett, M Larson, A Carville, K Ellis, I 'The Expert Patient: The Key to Multi-Disciplinary Wound Care'

Beischer, A Cornoïu, A de Steiger, R Donnan, L Richardson, M 'The Use of Multimedia to Improve Patient Consent for Knee Arthroscopy'

Bichel-Findlay, J Callen, J Sara, A 'An Information System's Contribution to Work Satisfaction: Differing Perspectives between Doctors and Nurses'

Bishop, J Bishop, A 'Looking Forward in Tracking Mental Illness'

Boyle, D Liaw, ST Morrison, I Cross, M 'Can Australian GPs Trust Their Software?'

Boyle, J Karunanithi, M Chan, W Colavitti, C 'Benefits Realised by the EHRC Ambulatory Monitoring Project'

Brophy, J Edbrooke, A Eddy, A 'A Trial of Digital Pen Technology'

Buist, M 'An innovative information system to improve patient safety in the general ward environment – "Patientrack"'

Calabretto, J Lewis, B Reeve, J 'A preliminary investigation of an integration tool to improve access to information resources in clinical software'

Callen, JL Braithwaite, J Westbrook, JI 'Does the Clinical Environment Affect the Use of Computerised Physician Order Entry?'

Callen, J Paoloni, R Prgomet, M Georgiou, A Robertson, L Westbrook, J 'Can Information Technology Improve Test Result Follow-Up?'

Cordwell, T 'The ageing population, accessing services with the help of technology'

Donnan, L Beischer, A Cornoïu, A De Steiger, R Graved, S Richardson, M 'Technology Mediated Learning in Healthcare: When a Picture Paints a Thousand Words'

Georgeff, M Hilton, J 'The Use of CDMS for Collaborative Care (Wagner Chronic Core Model

Georgiou, A Westbrook, J Nicolarakis, P Hordern, A 'Medical service innovation in residential aged care – an evaluation of the HealthCube ICT-enabled comprehensive medical assessment service'

Gogler, J Hullin, C and Mu N 'Allergies and Alert Recording in a tertiary Victorian hospital: paper and electronic health records to improve patient safety'

Kwang, CY 'King Island Brie Model: the role of health informatics in medical error management'

Lassere, M Rappo, J Gellately, W Iedema, R 'Risk to Privacy versus Benefit of Quality Care: What Do Patients with Chronic Medical Conditions Choose'

Parle, A Lassere, M 'Engaging the Clinician: The Value of Rapid Prototyping of 'Lightweight' Electronic Health Records'

Lassere, M Johnson, K Rappo, J Gellately, W Iedema, R Parle, A Rubin, G Sara, A Stelter, K 'Use of Patient-Held Paper-Based and Electronic-Based Portable Health Files (PHFs) To Facilitate Reliable Health Knowledge Transfer among Direct Health-Care Providers and Their Consumers-Patients: A Clinical Trial'

Li, J Callen, J Georgiou, A Westbrook, J 'The challenges of using technology in a busy Emergency Department: a case study of a next generation ED management information system'

Margelis, G 'Mobile Point of Care Solutions for improving Quality and Safety'

Nable, R Macdonald, P Edgecumbe, J 'Widespread Uptake and Use of a Primary Care Data Tool by General Practices in Victoria'

Richman, R Cullen, J Laurens, J Tsaprounis, G Segart, N Bourke, R, 'High Returns Pharming COWs'

Rushton, S Bichel-Findlay, J Ward, R Sinclair, S 'Using and It Platform to Deliver Standardised Cancer Information at The Point of Care'

Schweikert, P Everett, P 'Towards a Better Patient Outcome'

Soar, J Wang, Z 'Information for guided chronic disease self-management in community settings'

Stanek, J Symon, B 'SNOMED-CT Coding in General Practice – Barriers and Opportunities'

Stevens, G 'Mirrijini Dispense System (MDS) Managing Medicines in remote Aboriginal Clinics'

Stevens, G 'Prompting and monitoring patient compliance using SMS Medication Support System'

Tse, J Trumble, S, 'Information Mastery and Online Skills to Enhance Clinical Practice - a Study of General Practice Trainees'

Tse, J O'Shea, C 'Getting runs on the scoreboard – development of a formal health informatics curriculum statement for the RACGP'

Health Technology

Ashton, D 'A Practical Implementation of a Two Level Archetype Based Clinical Model'

Bennett, J 'Reliable, Secure, Confidential and Safe Integrated Healthcare Record Sharing'

Brown, A Pittmann, M Baylie, U 'Multi System Interoperability using Internet based Technology and a Federated Architecture'

Browne, E 'Representing Clinical Concepts – HL7 RIM shortcomings impede information sharing'

Cacayan, B Davis, J Patrick, J Zhou, Y, 'Automated Ontology Mapping: A Multi-level Approach'

Dinh, D Dink, M Yee, K 'Alphastudy.com, bridging the healthcare knowledge gap and creating a faster route to knowledge dissemination'

Flabouris, A Nicholls, V 'Geospatial solutions for Critical Care Resource Evaluation and Planning'

Garde, S Hovenga, E Granz, J Foozonkhah, S Heard, S 'Towards a Repository for Managing Archetypes for Electronic Health Records'

Garrett, J Stowasser, D Fahey, M O'Connor R, Clarke, L 'Extracting Existing Usage Data to Predict Future Requirements in Oncology and EMRs'

Grain, H Hovenga, E 'Challenges in health data – secondary data, modelling meaning'

Gu, Y Stanek, J Warren, J 'Knowledge Management (KM) Technologies in Medical Genetic Testing (MGT) Laboratories - a Literature Review'

Hansen, D Lawley, M Vickers, D Ryan-Brown, J Harrap, K O'Dwyer, M Melki, K McBride, S 'Accessing Patient Data for Chronic Disease Management'

Hansen, D 'Access to Distributed Data while Preserving Patient Privacy'

Hansen, D Giermanski, M Dujmovic, M Passenger, J and Lawley, M ‘Building SNOWMED CT Reference Sets for use as Interface Terminologies’

Helal, M Sintchenko, V ‘Dynamic programming algorithms for discovery of antibiotic resistance in microbial genomes’

Hicks, R ‘Foundational Principles for Databases: Isolated or Interoperable (EHR)’

Ho, J Ribeiro, J Williams, S, ‘Review of the Healthcare Client and Provider Identification Standards’

Hockings, C ‘Imagine there’s no passwords...’

Khambati, A Warren, J Grundy, J Hosking, J ‘A Model Driven Approach to Care Planning Systems for Consumer Engagement in Chronic Disease Management’

Lam, M Georgiou, A Westbrook, J ‘Record Linkage – A Method to Generate an Enriched Dataset for the Student of CPOE Systems on Test Turnaround Time’

Le, Q Health Informatics in the Eyes of the Overseas-Born Health Professionals

Leslie, H Heard, S ‘Archetypes 101’

Lewis, B, ‘An Electronic Clinical Audit Application for General Practice’

Liaw, S Boyle, D ‘Secure Data Linkage and Information Sharing With GRHANITE’

Lin, F ‘The Role of Data Mining in Predictive Medicine: A Narrative Review’

McBride, S Ryan-Brown, J Harrap, K ‘Linked Data: First, low cost semantic interoperability for health care?’

Madsen, M ‘A Health Information Privacy Ontology: Toward Decision Support for Compliance Assessment’

Maeder, A ‘Telehealth Standards Directions Supporting Better Patient Care’

Nugrahanto, S Morrison I ‘A Design Science Approach to Modeling and Facilitating Workflow and Decision Making’

Nguyen, A Lawley, M Hansen, D Colquist, S ‘A Simple Pipeline Application for Identifying and Negating SNOMED Clinical Terminology in Free Text’

Patrick, J Budd, P ‘Automatic Conversion of Clinical Notes into SNOMED CT at Point of Care’

Patrick, J Ly, R Truran, D ‘Evaluation of a Persistent Store for OpenEHR’

Patrick, J Wang, Y Miller, G O'Hallaran, J, ‘Automatic Mapping ICPC2-PLUS Terms into SNOMED CT Terminologies’

Patterson, A ‘A Case against Centralised Shared Electronic Health Records’

Readshaw, N ‘Security as a Service – A Low Risk Approach to Integrating with NEHTA’s Security Specifications’

Ryan, A Ekland, P ‘Ontology Mapping between HL7 Versions 2 and 3 and OpenEHR for Observations Messages’

Schloeffel, P Beale, T Hayworth, G Heard, S Leslie, H ‘The Relationship between CEN 13606, HL7, and OpenEHR’

Scott, P McIntyre, A Davison, J Tattam, P ‘Use of GELLO v.1, GLIF 3.5, SNOMED-CT and EN13606 archetypes’

Thurston, LM ‘Flexible and Extensible Display of Archetyped Data: The OpenEHR Presentation Challenge’

Truran, D Saad, P Zhang, M Innes, K Innes, K Kemp, M Huckson, S Bennett, S ‘Using SNOMED CT – enabled data collections in a national clinical research program; primary care data can be used in secondary studies’

Tsafnat, G Sanden, L Kaeseler, N ‘New Decision Support Paradigm for Bioinformatics in Antibiotics Prescription Support Systems’

Vickers, D Lawley, M ‘Mapping existing medical terminologies to SNOMED CT: An investigation of the novice user’s experience’

Management

Best, D ‘Patient Home Monitoring with Telehealth Technologies in Queensland Health’

Boyle, J Lind, J Green, D Crilly, J Miller, P Wallis, M Jessup, M Fitzgerald, G ‘Analysis of Patient Presentation and Admission Data for Prediction Modelling’

Buckland, G Stanczak, J 'Save &100,000's per year with independent ECG management'

Conley, C Wagnerien, B 'W-Fi Asset Tracking and Management for the Healthcare Enterprise.

Counter, M 'Statewide Paperless Health Record for Queensland Sexual Health Clinics'

Curry, J McGregor, C Tracy, S 'Incorporating Balanced Scorecards into the Patient Journey Modelling Process'

Donaldson, P Sahama, T 'Identifying and using eHealth phobias to implement communication protocols and change cultural and social behaviours in eHealth'

Ferris, N MacIsaac, P McCauley, V Lindop, C Eichlberg, M Grimm, J 'Towards Delivery of Digital Diagnostic Imaging – Collaboration to Reach a Solution'

Forsythe, J MacDonald, A Wilhelm, E Strachan, M Evans, D 'Efficacy of electronic discharge summaries: a case study demonstrating early results at two hospitals'

Fuchter, E Herlihy, R Shalloo, N 'Managing a State-wide eMR Clinical Transformation'

Georgiou, A Lam, M Westbrook, J 'Monitoring the Impact of CPOE on Healthcare Delivery – A Benefits Realisation Approach'

Green, R Joyce, P, 'Systemic Issues of the Information System in the Healthcare Industry: Lessons Learned from the Field in Australia'

Guest, G Green, R Bourke, J Lin, F Watters, D 'Mind the Gap: Minimising the Risk of Missing Pathology or Failing to Carry Out Planned Follow Up'

Hobson, C 'Economically Effective Health Information Management'

Justin, L Hanson, R Fan, C Gehrig, M Dent, De Venables, P 'Costing Adverse Events by Linking Incident Monitoring and Clinical Costing Systems'

McDonald, T Hardy, J Kwok, C Lee, C 'Implementing Technology-Based Care and Management Systems for Effective Aged Care Outcomes: Issues and Recommendations'

Ratnayeke, A, Implementing eReferral and Service Coordination in the Health and Community Sector from the bottom up

Richman, R Chan, L Whiteley, J Roberts, A Lippiatt, D Farrell, P 'No longer Lost in Translation'

Royle, E Germann, S 'Careconnect.sa Datawarehouse Information for Improving Quality'

Steele, C Connors, T Smolenaers, F 'The Impact of Rapid Roaming User Access on Workforce Efficiency in Aged Care'

Tang-Taye, J Turner, A 'Is a Health and Wellness program based on Telehealth profitable in a workplace environment? A managerial approach'

Thomas, D 'Paper-based or paperless? Challenges and Realities of removing paper from the Medical Record'

Tipper, S McDonnell, G 'Understanding the Dynamic Complexity of Medical Technology: A Systems Approach'

Unnithan, C Smith, R Fraunholz, B 'Maximising the Benefits of Radio Frequency Identification Technology (RFID) Integration in Clinical Contexts: a Linear Conduit'

Stevens, G 'eWebstercare online ordering and communication system'

Nursing

Gogler, J Hullin, C Mu, N 'Allergies and Alert Recording in a Tertiary Victorian Hospital: Paper and Electronic Health Records to Improve Patient Safety'

Gogler, J Hullin, C Monaghan, V Searle, C 'The Chaos in Primary Nursing Data: Good Information Reduces Risk'

Farrell, M Baldwin, I Weare, K 'Improving patient health outcomes in acute care hospital settings using mobile wireless technology and handheld computers'

Wade, V Izzo, J Hamlyn, J 'Videophone Delivery of Medication Management in Community Nursing'

Wang, N Yu, P Halley, D Oxlade, D 'Developing Approaches to Measure the Quality if Electronic versus Paper-based Nursing Documentation in Aged Care Homes'

Populations

Ahamed, T Gogler, J Hullin, C Morrison, I, 'Nursing Decision Support 'Needs' for Better Patient Management'

Akhtar, M Gallego, B Shiue, A Sintchenko, V 'Perspective Biosurveillance for Early Detection of Disease Outbreaks'

Besleaga, K Neill, D Kelly, J 'Identifying gaps in mental health services in a Local Government Area using GIS and data from clinical software'

Boyle, D Kong, F 'A systematic mechanism for the ethical collection and interpretation of display format pathology test results from Australian Primary Care records'

Doran, CM; Sara, AF 'If It Is for Free, Is It Really Worth It?'

Kearsey, I Peasley, K Truran, D 'Comparison of results between a re-coding audit and analysis by PICQ'

Lewis, N 'Health Informatics trends and issues – Telehealth'

Luanrattana, R, 'Strategies for Training Nurses to Work with Information Systems'

Plummer, V 'Informing Nursing Resource Management - a Study of TrendCare Data'

Madsen, M 'EHR Privacy Risk Assessment Using Qualitative Methods'

Margelis, G, Providing Disease Management to the masses: What role for ICT?'

Mok, M Osinski, M Barton, M Farrugia, H Giles, G, Chapman, A 'Implementation of Population Based Clinical Cancer Data For Gynaecological Cancers'

Pang, C Hansen, D 'Improved Record Linkage for Encrypted Identifying Data'

Sheldon, AB Hodges, BR Doran, CM Sara, AF, 'Climbing the Escarpment'

Ross, B Ientile, J Hadzanovic, L Merriel, R Hibbert, M 'Information Based Medicine and the Molecular Medicine Informatics Model (MMIM) Project'

Sintchenko, V Persson, L Lanser, J 'Communicable Disease Informatics - Emerging Concepts in Disease Surveillance'

Smith, M Harvey, R Abraham, N Hood, S Tannenbaum, D 'A Naturalistic Study of a Post-disaster Community Project Using Web-based Monitoring'

Scholarly

Alzougool, B Gray, K Chang, S 'Toward a Taxonomy of Information Needs of Informal Carers – A Case Study of a Carer of a Child with Diabetes'

Bain, C Raikundalia, G Ratnayake, K 'OPDSS: A Strategic Management Information System for Hospital Outpatient Departments'

Chan, Z Croll, P Hansen, D Maeder, A 'The Use of Agent Technologies for Preserving Privacy with Health Records when Linking Federated Databases'

Creswick, N Westbrook, J 'Social networks of staff in an emergency department'

Croll, P R Croll, J 'Privacy Compliance - Managing the Risks when Integrating Health Data'

Diment, K Yu, P Garrety, K 'Complex Adaptive Systems as a Model for Evaluating Organisational Change Caused by the Introduction of Health Information Systems'

Forsyth, R Maddock, C Broadbent, M Iedema, R Lassere, M 'Patient Attitudes towards Improving Their Care by Carrying Their Own Medical Information: A Qualitative Analysis'

Fry, B Warren, J, 'Supporting Multiple Navigation Paradigms in Internet-based Personal Healthcare Records'

Georgiou, A Westbrook, J McDonnell, G Magrabi, F 'Multi-method System Simulation Analysis as an Implementation and Evaluation Tool for Computerised Pathology Order Entry Systems'

Hafeez-Biag, A Gururajan, R 'Organizational, Technical & Perceived Readiness as Adoption Factors for Wireless Technology in Healthcare: An Australian Case Study'

Kelder, J Turner, P Lueg, C 'Supporting Community Knowledge Brokers: Information System Challenges in Breast Screening Service Delivery'

Lin, F 'Towards personalised pharmacotherapy: a perspective from biomedical informatics'

McLellan, S Galvin, M McMaugh, D 'Benefits Measurement from the use of an Automated Anaesthetic Record Keeping System (AARK)'

O'Dwyer, M O'Dwyer, J Melki, K Crilly, J Lind, J Wallis, M Keijzers, G Tippet, V Peters, J Bost, N 'Applied Data Linkage: from dirty data to clean complete patient records in Emergency Healthcare'

Ranasinghe, I Sahama, T Yaralagadda, P 'Evidence based healthcare planning in developing countries: An Informatics perspective'

Sahama, T 'Health Informatics Domain Knowledge Analysis: An Information Technology Perspective'

Sargent, J Eklund, P Ryan, A Burgess, L Cooper, J Alcock, C Ryan, D, 'Mobile Information Access and Diffusion in Ambulatory Care Service Settings'

Sayer, G Whicker, S Marshall, P 'Use of Electronic Patient Management Systems and the Impact of Drug Interaction Warnings: the General Practice Research Network'

Turner, P Wong, MC Yee, KC, 'Understanding Interactions of Factors Influencing Clinical Handover: Insights for Information Technology'

Williams, P Mahncke, RJ, 'Primary Care Information Security: A Case for Practical Assistance'

Wong, MC Yee, KC, 'Clinical Handovers: Two Sides of a Coin'

Wong, YK 'A Model for HealthCare System Quality'

Xie, J Burstein, F Evans, J 'Intelligent Support for Resource Quality Evaluation and Description in Health Information Portals'

Appendix 3: Papers with a critical orientation

1993

Southon, F Yetton, P Burton, S 'Information Technology in a Hospital – A case study'

2006

Whetton, S 'Health Informatics: Who Am I (and Does It Really Matter)?'

2008

Croll, P 'Privacy Impact Assessments – the Organisational versus the Individual's viewpoints'

Publications arising from this thesis

Whetton, SG 2005 'Health informatics workforce skills: technology is king, time for a consort?', *Proceedings of HIC 2005: Thirteenth National Health Informatics Conference*, 31st July - 2nd August, Melbourne, Australia, pp. 1-7

Whetton, SG 2006 'Health Informatics: Who am I (and does it really matter)?' *Bridging the Digital Divide: Health Informatics Conference Proceedings 2006*, 20-22 August 2006, Sydney

Whetton, SG & Georgiou, A 2010, 'Broadening the Socio-Technical Horizons of Health Informatics', *Open Medical Informatics Journal*, vol. 4, no. 1, pp. 179

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Hordern, A Georgiou, A Whetton, SG & Progmet, M, 2011, 'Consumer eHealth-an overview of the research evidence and the implications for future policy', *Health Information Management Journal*, vol. 40, no. 2, pp. 6-14